

**FERTILITY DESIRES OF WOMEN LIVING WITH HIV/ AIDS IN NORTHERN
BRITISH COLUMBIA**

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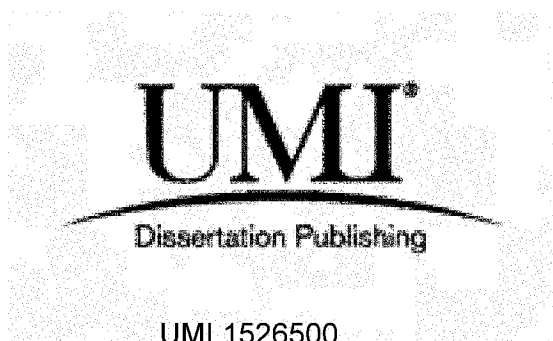
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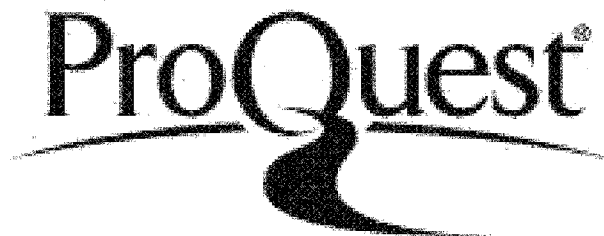
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ABSTRACT

The fertility issues of people living with HIV/AIDS (PLWHA) are increasingly becoming very important because advances in medical care have decreased the risk of HIV transmission from mother to child. Thus many PLWHA are now opting for parenthood. Within the northern region, the proportion of HIV is higher in both Aboriginal and non-Aboriginal populations, more so than in other areas of Canada. There is little information known on the fertility desires of women living with HIV in the rural northern community. This study used a mixed methods design by first implementing a quantitative structured survey (Phase I) and then a qualitative follow-up semi-structured interviews (Phase II). The purpose of the study was to determine the socio-demographic, reproductive characteristics, and the fertility desires of women living with HIV/AIDS. Phase I, the structured survey explored the fertility desire and reproductive intentions of 21 HIV positive women and also assessed the relationships between their fertility desires and, socio-demographic and reproductive characteristics. In Phase II semi-structural interviews were conducted with four HIV positive women to increase the depth of understanding of what these women thinking and feeling about fertility desire. In this research, the majority of the participants (52.4 %) were within the age group of 30- 39 and 66.7% were of Aboriginal descent. Half of the participants (47.6%) reported desire to have children in future. High proportions of the women (80%) were sexually active. Usage of barrier methods as birth control decreased to nearly 25% after diagnosed with HIV. There were statistically significant relationships observed between the fertility desire and ethnicity ($\chi^2 = 5.51$, $df=2$, $p = .05$) and, partner's preference to have children ($\chi^2 = 23.9$, $df= 2$, $p = .001$). A positive correlation was observed between the age of the participants and the participants youngest child age ($r = .74$, $df= 19$, $p <.005$). Women of younger age and those who had younger aged youngest child expressed desire more desire for children in future. Fertility desires of women were influenced by their age, ethnicity, age of their youngest child and, also the desire of their partner to have children. Many of the women remained committed to having children despite of their HIV status. Women's most common fertility intention was to feel motherhood and to experience family life; this outweighed their financial constraints, lack of available support and services, stigma around HIV, and unsupportive health care provider attitudes. Participants expressed confusion about their chances of transmitting the virus to their children. Health care providers and policy makers need to consider and plan for additional support and services to help the HIV-infected women achieve their fertility goal. Future research is recommended for better understanding of the fertility issue among HIV positive people living in the rural northern community.

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retro Viral Therapy
CINHS	Central Interior Native Health Society
HARRT	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
PMTCT	Preventing Mother-to-Child Transmission
PLWHA	People Living With HIV/AIDs
STI	Sexually Transmitted Diseases
UNAID	United Nations Programme on HIV/AIDS
UNPF	United Nations Population Fund
WHO	World Health Organization

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CHAPTER ONE: INTRODUCTION

I witnessed a situation which shows the importance of the topic I chose for my research. At an outreach activity meeting about marginalized HIV patients, a healthcare provider presented the case of an HIV positive woman who desperately wants to have a child with her partner (HIV negative man). She is a homeless woman in her late 30s who has had tubal ligation earlier in her life. The woman has clearly articulated to her health care provider her desire to conceive a child through artificial insemination (AI). She requested assistance in obtaining an appointment with a physician so the AI process could be started. Her request faces several obstacles. AI is not available in Prince George for people living with HIV. Therefore she would need a referral and would need to travel to Vancouver for further assistance. The health care provider describing the situation was clearly dismissive about the woman's need, even laughing during the narration. This attitude towards the woman's desire for a child strongly illustrates the timeliness and necessities of this research. It reinforces the thesis developed here, that people living with HIV see a future for themselves and that a woman's desire to have children is not precluded by a positive HIV diagnosis.

Background of Study

Fertility refers to the actual reproductive performance of an individual, a couple, a group or a population (Haupt, Kane, & Haub, 2011). It may also be defined as the indication of actual reproductive performance of a woman or group of women in terms of the number of children born to her or to them (Singh, 2006). The level of fertility of a population is partly influenced by demographic factors like age-sex distribution, marriage rate, and the number of married couples. It also depends on many other prevailing social, economic, and cultural conditions as well as the level of development that the country has attained. Fertility desires are the most proximate determinants of actual childbearing behaviour of a population

(Fishbein & Jaccard, 1973; Pritchett, 1994). Fertility desire is a value that develops under certain socioeconomic cultural and political conditions, reveals people's wills and desires for the number of children, reproductive period, and gender preference. As a social phenomenon, fertility desire or childbearing behaviour has "Three-Dimensional Characteristics", quantity, timing, and gender (Baochang, 1992).

Cultural norms strongly influence what should be the desirable family size. The "desired number of children" is an expectation of the number of children in one's lifetime under certain socioeconomic, cultural, and political situations. The desired number of children is also known as "ideal number of children" and/or "expected number of children". Desired timing of childbearing includes the ideal age at first childbearing and ideal interval of childbearing between first and second parity. Ideal age at first childbearing is the ideal age the couples want to have their first child; ideal interval of childbearing between first parity and second parity is the time between the birth of the first child and the birth of the second child. Desired childbearing gender refers to the parents' preference for one gender over the other (Singh, 2002).

There is widespread pressure on couples and particularly on women to have children. In some cases there may be cultural pressure to continue childbearing if the desired number of the preferred gender has not been achieved (Withers et al., 2013). As a result of this pressure, HIV-positive couples who have no children or who have one or two children, may choose to have additional children in spite of their HIV status, confirmed or not. Whatever is their drive to have children in the future, HIV positive women need accurate information, empathic and unbiased counselling about the risk of transmitting HIV to their infants during pregnancy, delivery, and breastfeeding, including risk reduction through good adherence to treatment (Craft, Delaney, Bautista & Serovich, 2007; Ogilvie et al., 2007; Withers et al., 2013).

HIV and Highly Active Antiretroviral Therapy (HAART). There is no cure for HIV/AIDS. However, treatment with antiretroviral drugs can delay the onset of AIDS and allow someone to live with the HIV infection for many years without becoming ill. The development of multi-drug combination therapy for treatment of HIV disease is considered one of the great success stories of modern medicine. In a period of approximately ten years, the death rate from HIV disease was reduced by 50 – 80% and changed from a nearly universally fatal and catastrophic illness to what is now often a manageable chronic illness (Delaney, 2006; Samji et al., 2013). Research evidenced that in North America, a 20-year-old HIV-positive adult receiving Anti-Retroviral Therapy (ART) shortly after becoming HIV positive is expected to live into their early 70 s, a life expectancy approaching that of the general population (Samji et al., 2013). Combination of several (typically three or four) antiretroviral drugs is known as HAART. HAART causes a sustained suppression of HIV multiplication and hence reduction in the amount of virus in the body and, restore the body's ability to fight infections (immunity). It also improves quality of life, prolongs life, and also reduced chances of mother to child HIV transmission (Bitnun et al., 2014; Samji et al., 2013)

Problem Statement

Fertility issues of HIV-positive men and women are becoming increasingly important (Loutfy et al., 2012; Chen, Philips, Kanouse, Collins, & Miu, 2001). Despite the growing importance of fertility issues, little is known about their actual desires and how the desires vary by individuals' social and demographic characteristics (Chen et al., 2001). The fertility desires of this group of people will pose a threat to the preventive strategies against vertical and heterosexual transmission of HIV. Mother-to-child transmission accounts for over 90% of HIV infections among young children (WHO, 2010). Without treatment, 30% of infants born to HIV-infected women will become infected during pregnancy, in labour and delivery, or through breastfeeding (UNAIDS, 2008; Info report, 2006). Thus, in view of the UNAIDS

(2008) and Info reports (2006) of the increasing number of HIV-positive men and women, it is important for the healthcare providers to place more emphasis on the risks of transmission, provide adequate information and support to HIV positive women to meet their reproductive need .

Half of the over 40 million people living with HIV/AIDS worldwide are women (Stanwood, Cohn, Heiser, & Pugliese, 2007); the same is true in Canada (HIV/AIDS Epi update, 2010). In Canada, more than 23% of new HIV infections occur in women and 80% of these women are in their childbearing age (Public Health Agency of Canada 2010; Ogilvie et al., 2007). According to UNPF (2007), the probability of HIV infection is 1.6 times higher in females aged 15- 24 than in men of the same age group. HIV/AIDS Epi update, (2010) reported that, 28.3% of total HIV positive women are aged 40- 49; while 39.9 % are aged 30- 39 and 17.9% are in age group of 20 -29. In view of the high proportion of women living with HIV/AIDS in the 15-49 years age group in Canada, HIV positive women within this age group were included in this study.

Evidence showed that, HIV infected women face multiple difficult issues such as fear of disclosing their HIV status, stigmatization, societal pressures to bear children, and the effect of pregnancy on their health (Ingram & Hutchinson, 2000; Nattabi, Li, Thompson, Orach, & Earnest, 2009). Young women acquiring HIV through heterosexual contact are the new wave of the epidemic (Stanwood, Cohn, Heiser, & Pugliese, 2007). The advent of HARRT provided the HIV-positive women new opportunities, such as the possibility of parenthood and increased life expectancy (Wagner et al., 2010). The advances in medical care have decreased the risk of mother-to-child-transmission among mothers taking ART to about 2% and also have improved the prognosis for the HIV. Now HIV positive men and women are considering childbearing and parenthood (Chen et al., 2001). Research shows that, in Canada and other developed countries, mother-to-child-transmission was reduced to

0.1% if the mothers adhered to HARRT for at least 4 weeks before delivery but for women with HIV, becoming a mother brings with it challenges beyond what HIV-negative mothers experience (Bitnun et al., 2014; Loutfy et al., 2009; Ogilvie et al., 2007). Research in Canada showed that, fertility desires and expectation to have children among women living with HIV are similar to HIV negative women (Loutfy et al., 2009; Ogilvie et al., 2007; Payne, 2003).

Rationale for the Study

The desires of HIV-infected persons to have children in the future have significant implications for the transmission of HIV to sexual partners and the newborn child. Although the risk of mother-to-child transmission can be decreased with prophylactic treatment, maternal transmission accounts for most new HIV infections in children (Cressey & Lallémand, 2010; Teasdale, Marais, & Abrams 2011). Research evidenced that in Canada, more than 25% of new HIV infections occur in women, despite this, the reproductive health needs of women living with HIV did not receive the attention they deserve (Loutfy et al., 2012; Ogilvie et al., 2007). Addressing this knowledge gap is very important because most HIV positive women, worldwide, are in their reproductive age (UNAIDS 2005). Additionally, with widespread availability and use of HAART, women with HIV can enjoy the same health benefits, status and life expectancy as the general population (Moore, Sabin, Johnson & Philips, 2002; Gange et al 2002).

In Northern British Columbia the rate of HIV infection is 9.5/100,000 population. This is higher than the rate of overall British Columbia, which was 7.5 /100,000 population (HIV/AIDS Epi update, 2010). In Canada, the rate of new HIV infections is higher among the Aboriginal peoples than non-Aboriginal people; the estimated rate is about 3.6 times higher. The Aboriginal people are more susceptible to HIV infection as they are unreasonably affected by social, economic, and behavioural factors which lead their communities to high rates of substance abuse, poverty, and inadequate accessibility to health care services.

Consequently these factors place the Aboriginal people with higher susceptibility to HIV infection and other sexually transmitted infections (Catie.ca, 2015; Phac-aspc.gc.ca, 2015).

In spite of little information on the fertility needs of women with HIV and high rate of HIV infection in the Northern British Columbia, a literature search revealed only one study (Ogilvie et al., 2007) conducted in the broader sample of entire British Columbia. These findings were based on the year between 2003 and 2004 did not provide a complete picture of fertility desire among the women living with HIV in Northern BC in general and Prince George specifically. Thus, this proposed study will provide women with HIV and the health providers with comprehensive information regarding reproductive issues, and assist in planning for health and social services including pregnancy planning, healthy preconception lifestyle, and contraception, as well as minimising HIV transmission to their partners and the newborn. It may also help in establishing a health agenda on priority issues concerning reproductive needs for women living with HIV in rural remote areas of the Northern British Columbia.

Objectives of Study

Overall the study objectives were to determine the socio-demographic and reproductive characteristics, and the fertility desires of women living with HIV/AIDS in Northern Interior (Prince George). This study specifically

- identified the socio-demographic characteristics of the participants,
- determined the fertility characteristics and desires of the study participants,
- investigated the relationship between participants' socio-demographics and reproductive characteristics and, their fertility desires,
- gained increased depth of understanding of HIV positive women thinking and feeling about the fertility.

Scope of the Study

This research had two phases. Phase I is a quantitative analysis of the socio-demographic and reproductive status, fertility desires, and the contraceptive behaviours of women living with HIV in Northern Central BC (Prince George). This phase also evaluated the participants' reproductive intentions. Research participants' opinion on the reasons why they intend to have, or to not have, children in the future were obtained in the qualitative survey. In Phase II, reproductive intentions of the participants, their thoughts and suggestions regarding issues related to fertility were explored through in depth interviews with the participants. Information collected from this research offers a platform for health care providers to support the women living with HIV to achieve their reproductive potentials in the coming years by influencing social policy, community programming and health services in the north.

Situating Myself as a Researcher

I, Dr Farzana Amin (M.B.B.S. & MPH), am an UNBC graduate student candidate in the Masters of Health Science program. I am an international medical school graduate who is not currently licensed to practice medicine in Canada. As a general practitioner, my professional training includes Gynaecology, Medicine, and Public Health. My professional experience entails working with marginalized women to meet their medical needs. The combination of my professional training and experience as a medical doctor gives me, as a researcher, a unique and well-informed insight into the importance of this study.

My rationale for engaging with this area of research comes from my experience in my home region. In Southeast Asia women are heavily oppressed generally. There is poverty, gender discrimination, cultural and societal issues; lack of availability and access to health care services leaves women as a vulnerable group. I see similarities of various women's health issues in Prince George and my country, where there is poverty, limited access to

health care facilities, colonization, and other social issues which makes HIV-positive women a sensitive and vulnerable group of people. As a female medical graduate, I am always interested in women's health issues and HIV/AIDS. I have vested interest in contributing to the health of oppressed and marginalized populations due to my experiences in my home country. As a woman, I feel that most woman, either HIV positive or HIV negative would desire to have children; however this decision could be complicated by their HIV positive status. HIV positive women may find themselves more marginalized and facing difficulties regarding the decision to have a child (ren), or no children.

As a non-practicing physician and graduate-level researcher, I can contribute to the wellbeing of these marginalised women by conducting research in this area and gathering information about women living with HIV and their reproductive desires. It is an opportunity for me to conduct this research about HIV positive women's fertility desires in the north, an opportunity to understand them and their child- bearing nature under the guidance of highly qualified and experienced researcher of the University of Northern British Columbia.

CHAPTER TWO: LITERATURE REVIEW

A literature review was conducted using electronic databases relevant to the areas (HIV, reproductive health and fertility desire /intention of PLWH) were accessed through the Internet. Peer- reviewed journals, books, newsletters/websites, reports and policy documents from governmental and non-governmental organisations were included. The reference lists of retrieved papers were checked for other key papers in order to ensure a comprehensive search. The following databases were searched: PUBMED, Google scholar, science direct, UNBC library, and Medline. The search strategy included all aspects of HIV and reproductive health of PLWH. This was accomplished by using the key words such as “HIV and reproductive health of PLWH”, “HIV and fertility desire of PLWH”, “HIV and fertility intention of women living HIV”, “ HIV and Pregnancy”, “Reproductive health care for PLWH” “HAART and Pregnancy”, and “HIV and fertility”.

The reproductive guidelines during the early years of the HIV pandemic recommended that HIV-infected patients must avoid pregnancy (Duerr, Beckerman, & Soriano, 2006; Sagara, 1992). As there was poor prognosis of HIV infection and high risk of transmission of HIV to sexual partners and newborns, the Centre for Disease Control and Prevention (CDC) and the American College of Obstetrics and Gynaecology, strongly discouraged HIV-infected women from becoming pregnant and had advised against any reproductive attempt. The American Society for Reproductive Medicine suggested other alternative options such as donor insemination or child adoption (Barreiro et al., 2006). However, during those early days of medical response to HIV, the norm was much restricted reproductive possibilities and with high risk of sexual and/or vertical transmission of HIV, many HIV-positive individuals desire to intend pregnancy was discouraged (Selwyn et al., 1989).

There has been remarkable progress in the management and prognosis of HIV infection over the last decades. The administration of combination of triple antiretroviral regimens allows complete suppression of viral replication and significant improvement of the immune status in most patients. This has dramatically changed the natural course of the infection, which is now considered a chronic illness for most, at least in developed countries (Barreiro et al., 2006).

HIV/AIDS and Fertility

As described by United Nations (2002), the relationship between HIV/AIDS and fertility is a complex one. First, the causality can run in either direction. While HIV/AIDS can affect fertility desires and outcomes, it is also possible for fertility to affect the risk of HIV/AIDS and disease progression. Second, HIV/AIDS and fertility may share common causes that induce an association between the two.

The effect of HIV/AIDS on fertility can differ not only in magnitude but also in direction and this effect which can be positive or negative, may operate both at the individual level and at the aggregate level (United Nations, 2002). At the individual level, the interplay occurs through two channels: the biological one, which is due to the physiological consequences of the disease on fecundity and its subsequent effect on the population structure, and the behaviour-response channel, which includes a change in fertility preferences of both those that are HIV-positive and those that are not, as well as changed sexual behaviour to avoid infection. The biological impact works through various mechanisms that all seem to point towards reduced fertility among HIV infected women. The most important ones are believed to be higher rates of miscarriage and stillbirth, co-infection with other sexually transmitted diseases, menstrual dysfunctions, weight loss leading to amenorrhoea, and less frequency of intercourse because of illness, and of premature death of regular partner (Fabiani, Nattabi, Ayella, Ogwang, & Declich, 2006; Zaba & Gregson, 1998).

A study conducted between 2003 and 2004 in a broader sample of 39 sites in British Columbia determined the desire of fertility among HIV-positive women. In this study, 30% of the sample reported the desire to have children in the future. This rate is comparable to that of the general population (Ogilvie et al., 2007; Payne, 2003). The implication is that Canadian women appear to have similar reproductive intents regardless of their HIV/AIDS serostatus (Ogilvie et al., 2007). A reasonable understanding of the impact of HIV/AIDS on fertility requires an examination of the impact both at the individual level as well as at the aggregate level (Arrehag, De Vylder, Durevall, & Sjoblom, 2006; Epstein, 2004; Ntozi, 2002).

Pregnancy and HIV/AIDS

Pregnancy after HIV diagnosis has been associated with relationship stability (Isabelle et al., 1997; Benthem, et al., 2000), reduced sexual activity (Muller, Sarangbin, Ruxungthan, Sittitrai, Phanuphak, 1995) and contraception use (Benthem et al., 2000; Murphy, Rotheram-Borus & Reid, 1998). For example, in a study conducted in two Sub-Saharan countries (Kenya and Tanzania) to investigate the impact of HIV voluntary counselling and testing on reproduction planning among HIV infected people found higher follow up pregnancy rates among women who were younger, had less than three children, were not using modern contraceptives, and were newly diagnosed with HIV. The study also showed higher partner pregnancy rates among men who were married or cohabiting, not using modern contraceptives, planning a pregnancy and aware of risk of vertical transmission (Forsyth et al., 2002). A study in the United States of America, using the nationally representative of HIV Cost and Service Utilization Study (HCSUS) used the sample of HIV positive women, reported that 12% of all women and 26% of women younger than 30 years had children after HIV diagnosis (Schuster et al., 2000).

With the advancement of HIV treatment and increased accessibility and availability of HAART, HIV infected women are now living healthier lives and have a different outlook on future family planning (Nakayiwa et al., 2006; Nancy, 2007). Pregnancy planning for PLWH is an increasingly important component of HIV management (Loufty et al., 2009; Ntozi, 2002; Ogilvie et al., 2007). Therefore, it is important to understand the fertility desires of the women living with HIV in order to develop programs to support them and their current and future counterparts in planning safer pregnancies that protect the health of the women, their partners and children (Loufty et al., 2009).

Family Planning and HIV

HIV/AIDS is one of the most disastrous and devastating afflictions of human history, sparing no country. Contraceptive services for HIV-positive women are one of the four cornerstones of a comprehensive program for prevention of mother-to-child transmission of HIV, (PMTCT). Preventing unintended pregnancy among HIV-positive women is an effective approach to reduce paediatric HIV infection and vital to meeting HIV-positive women's sexual and reproductive health needs (WHO, 2002; USAIDS, 2011).

Unprotected sexual activity carries risks for sexual transmission and vertical (mother to child) transmission of HIV (Baral et al, 2011). Many PLWHIV continue to be sexually active and some have strong desires for biological children (Cooper et al., 2007; Myer, Morroni, & Rebe, 2007) which entail unprotected sexual intercourse. In Ontario, a team of researchers led by Dr. Mona Loufty has surveyed more than 400 HIV positive women and reported that, unintended pregnancies are relatively common among the women living with HIV. They found that 56% of HIV positive women's last pregnancies were unplanned and this rate was significantly greater than that has been reported for HIV-negative women living in Ontario (30%) (Loufty et al., 2009). Family planning has important implications for the prevention of transmission of STI, HIV and unintended pregnancy. Family planning

counselling is needed to facilitate informed decision making about pregnancy (Laher et al., 2009; Loufty et al., 2009).

Fertility Desire and HIV

In many societies, women's identities are defined by child bearing. The ability to reproduce affects social standing, individual recognition, partnership stability, and through these conventions, financial security. Being HIV positive modified but did not remove reproductive desire (Yudin, Shapiro & Loutfy, 2010). HIV infected women follow prevailing community norms, intend to have children, and view reproduction as socially and psychologically desirable (Wekesa & Coast, 2014). In sub-Saharan African countries a substantial proportion of women and men who are on HAART wish to have children (Richter, Sowell, & Pluto, 2002; Cooper et al., 2007).

HIV has had variable effects on fertility in different cultures, both for expectations and actual childbearing following the diagnosis (Chen et al., 2001; Myer et al., 2007). Childbearing desire in HIV-infected men and women in the United States was 29%, and there pregnancy intent was associated with better health, younger age, and fewer children (Chen et al., 2001). Young women likely have an expectation of childbearing, and are more likely to voice desire for pregnancy after diagnosis (Chen et al., 2001; Myer et al., 2007). Some HIV positive individuals wished to avoid pregnancy. Fears of partner and infant infection and having previously infected baby were important factors deterring some individuals from considering having children while others showed strong desire to experience parenthood, mediated by prevailing social and cultural norms that encouraged child bearing in society (Ogilvie, et al., 2007).

In United States, an overall result of a study involving 2,864 HIV-infected adults receiving medical care showed that 28-29% of HIV-infected men and women desire children in the future. Among those desiring children, 69% of women and 59% of men actually expect

to have one or more children in the future. The study also found that the fertility desires of HIV-infected individuals do not always agree with those of their partners: As many as 20% of HIV-positive men who desire children have a partner who does not and that generally, HIV-positive individuals who desire children are younger, have fewer children, and report higher ratings of their physical functioning or overall health than their counterparts who do not desire children (Chen et al., 2001).

Reasons for desiring children are diverse. A study in South Africa illustrate that the reasons for wanting children among the HIV positive men and women receiving ART were not HIV related, while reasons for not wanting children were HIV related, such as negative health effects for HIV-infected people, possibility of orphaned children, and fear of HIV-infected child (Myer et al., 2007). Additional determinants of fertility intentions reported in the literature among HIV infected women include having a regular partner, personal health concerns, support or stigmatization from family, influence of health care providers, having a child who died of AIDS and availability of ART (Kanniappan, Jeyapaul, & Kalyanwala, 2008; Myer et al., 2007; Ogilvie et al., 2007).

Conceptual Framework for Analysis of the Link between HIV/AIDS and Fertility

HIV/AIDS is likely to influence the fertility desires of individual women through a number of behavioural and biological factors; namely, marriage, contraception, breastfeeding, postpartum abstinence, fetal loss, pathological, and natural sterility. For example, fertility may decline in the era of AIDS because of delayed onset of sexual relations and age at first union; reduced premarital sexual relations and remarriage and increased marital problems and spousal separation; increased condom use; increased duration of postpartum amenorrhea (PPA); reduced pregnancy rates and increased fetal loss; increased prevalence of sexually transmitted diseases (STDs) (United Nation, 2002); and reduced frequency of sexual intercourse and production of spermatozoa. On the other hand,

HIV/AIDS may increase fertility through reduced breastfeeding, reduced postpartum abstinence, and increased infant mortality (Ntozi, 2002).

As discussed, HIV/AIDS may influence fertility through one or more behavioural or biological proximate fertility determinants. I proposed a conceptual framework (specified below) used for the analysis of the link between HIV/AIDS and fertility. This framework is heavily based on the work of other researchers notably Bracher and Santow (2001), Boerma and Weir (2005), Monica and Alfred, (2007):

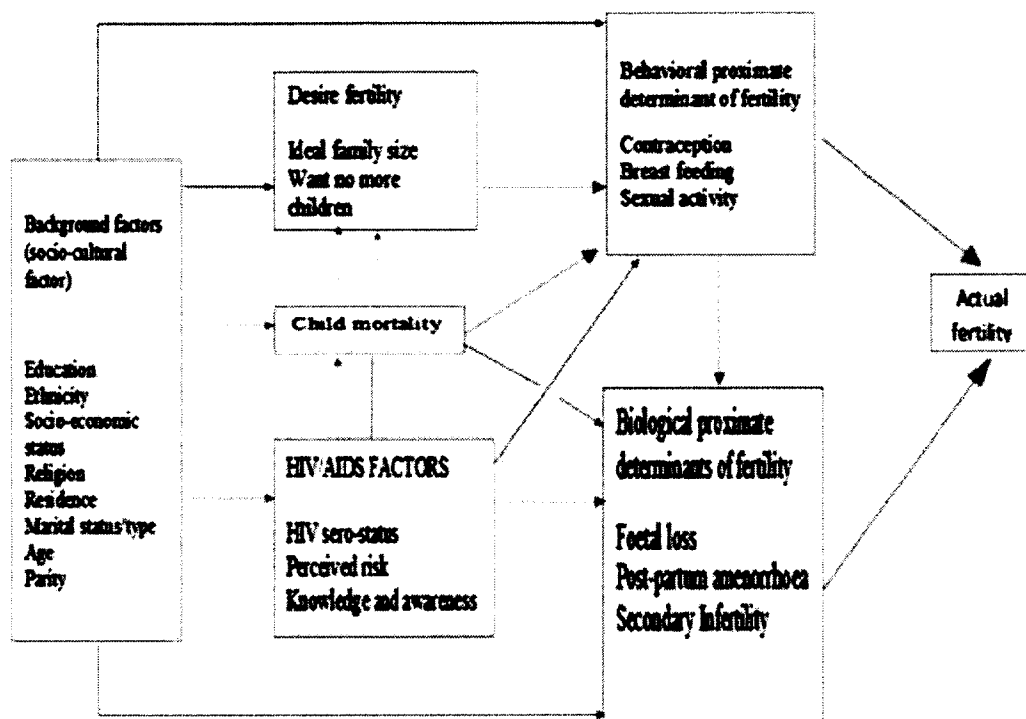


Figure 1: Conceptual framework for analysis of the link between HIV/AIDS and fertility.

There are complicated connections between fertility desire and HIV/AIDS (see Figure 1). There are HIV/AIDS factors, including sero-status, perceived risk and knowledge that may influence desired fertility either directly or through child mortality. Desired fertility in turn influences actual fertility through behavioural proximate determinants of fertility, mainly contraception. Alternatively, HIV/AIDS factors may directly influence the behavioural or biological proximate fertility determinants, which in turn influence actual fertility. A number

of factors in the background may influence desired fertility or proximate fertility determinants either directly or through HIV/AIDS related factors.

Studies in Kenya and Tanzania on the relationship between HIV/AIDS and fertility observed that an increase in child mortality can be expected to increase fertility, while an increase in adult mortality or concerns about AIDS would reduce fertility (Ainsworth, Filmer & Semali, 1998; Gyimah & Rajulton, 2004). To understand the link between HIV/AIDS care and reproductive health, including fertility options for people living with HIV and to describe attitudes towards parenthood and identify factors associated with desire to have children among men and women, a study was conducted in Brazil. The results showed that the desire to have children was more frequent among men than women and reported by 27.9% of participants (50.1% of men versus 19.2% of women). Male gender, younger age, having no children, living with 1-2 children, and being in a heterosexual partnership were independently associated with desire to have children (Paiva et al., 2007).

Summary of the Literature Reviewed

Review of more than thirty sources showed that there were many research studies conducted on similar topics in the African region, few in North America and Europe, but only one conducted in British Columbia (from the period 2003 to 2004). The need for further studies in British Columbia, particularly Northern British Columbia is obvious. With vast improvement of HIV/AIDS treatment and increase availability and accessibility of treatments, HIV/AIDS is no longer considered as a deadly disease but a chronic state like diabetes or asthma. Some research in African countries evidenced that fertility desire among people living HIV/AIDS was substantially high though lower than that of the general population and in British Colombia the rate of fertility desire among people living HIV is comparable to that of the general population. This change in the view toward HIV given medical improvements further necessitates new studies being done. In particular, health care

providers need to be educated and current on the implications of these developments for their practice.

CHAPTER THREE: METHODS

This study used a mixed methods sequential explanatory design by first implementing a quantitative phase and then following up with a qualitative phase (Creswell, 2013). The rationale for this strategy was to first conduct a structural survey to explore socio-demographic and reproductive status, fertility desires and the contraceptive behaviours of women living with HIV/AIDS (Phase I). Second, Qualitative in depth interviews (Phase II) were conducted to increase the depth of understanding of what women with HIV/AIDS are thinking and feeling about the fertility desires. This approach offered methodological and data triangulation (Tashakkori & Teddlie, 1998), better enabling me to understand fertility intention related to HIV status of women in the north.

The research targeted to the general population within the northern Canadian context which was inclusive and was not focussed on any single demographic beyond the scope described as follows: identified as HIV positive women between the age of 15-49, the commonly accepted age of reproduction. The intent for this study was to function as a conceptual springboard that could result in discussions with women of reproductive age living with HIV in pertaining to their desires as to fertility. It is hoped that this research would benefit women living with HIV/AIDS in the coming years by influencing social policy, community programming, and health services. Findings of this research will be shared with the authorities of the two chosen locations and with the research participants in a lunch event organized by the researcher at the end of the study (after thesis defence and publication of this research by the UNBC). Academic conference presentation and publication in peer reviewed journals will be pursued.

Phase I (Structural Survey)

Research questions. Following are the two research questions answered in Phase I. Phase II was carried out in order to have a better understanding of the responses in Phase I.

- What is the fertility desires of the women diagnosed with HIV in the North Central Interior of British Columbia?
- What are the relationships between fertility desires of women living with HIV and their socio-demographic and reproductive characteristics?

Study population and participants. The Phase I involved a structured survey conducted on women, aged 15-49, and living with HIV/ AIDS in Northern British Columbia. Forty potential research participants were identified by the authorities of Dr. Abu Hamours' clinic and CINHS and 21 participants consented to take part in the survey (Phase I).

The study was conducted in Prince George at two sites, the clinic of Dr. A. A. Hamour and the street level clinic of Central Interior Native Health Society (CINHS). These are the two major health care providers for HIV in Prince George. Dr. Abu Hamour is an Infectious Disease Specialist who provides care for both Aboriginal and non-Aboriginal people of whole Northern British Columbia. The CINHS clinic provides HIV care primarily for Aboriginal people in Prince George.

Sampling methods. The researcher endeavoured to obtain responses from every potential respondent identified by either agency. However, I recognised that there was a possibility that people approached might not wish to volunteer. Thus the sample became a convenience sample of those willing to respond.

Data collection procedures. The quantitative part of this research consisted of a brief cross sectional survey for HIV positive women of reproductive age. Potential research participants were identified by the authorities of Dr. A. A Hamour's clinic and CINHS. Participants were contacted by the authorities of those aforementioned study sites, and after obtaining the positive response from their clients the researcher was provided with access to those potential participants in order to administer questionnaire for the study. Confidential information was provided to the researcher with informed consent from the research

participant(s). The researcher scheduled a date and time to administer the study questionnaire, and other applicable paper work, with the research participant(s) at the study locations. Data were collected by using a structured questionnaire with open and closed-ended questions. The questionnaires were administered by the researcher and completed by the research participants. Each participant took 20-30 min to complete the questionnaire. The data were collected over a twelve week period. The research participants indicated whether or not they would permit the collection of follow up information (clarification of information they provided for this study and for Phase II in-depth interview), after the completion of this study, through interviews by the researcher.

Content validity was assured with the use of questions based on an extensive literature research on reproductive decisions in women with HIV/AIDS and was also assessed by guidance of expert panel review of the supervisory committee. An honorarium (\$25) was provided to each research participant to help them with their transportation or other costs. This also indicated to the participants that we valued their time and effort. The introductory text of the questionnaire explained the purpose of the survey and for whom it was undertaken. The text reinforced the relevance of the survey to the respondents and gained their interest.

Instrument (Questionnaire). The questionnaire developed for the Phase I was compiled from three separate sources to derive applicable survey information that represent socio-demographic information, fertility and contraceptive information of the participants. Refer Appendix A for details pertaining to the relevancy and, details of sources and citation of the survey. The following surveys were the original sources for the questionnaire of the Phase I which were combined into one single modified questionnaire:

- Canadian Community Health Survey, Cycle 2.2, Nutrition : Income-related household food security in Canada (Health Canada, 2004)
- Survey on Fertility Desires and reproductive health services (Mindry et al., 2012)

- HIV Positive Birth Control Survey (Ogilvie et al., 2007)

Modifications were made to the combined questionnaire in order to address the context of this study, and for collection of relevant information for the study.

Variables and their measurement. The primary outcome variable was the stated fertility desires of HIV positive women. In addition, contraceptive use (before and after HIV diagnosis) and socio-demographic characteristics (age, race, religion, marital status, and presence of any children) was also measured as explanatory variables. The fertility desires of the participants were measured specifically with question #13, “Do you intend to have children in the future?” and question #21(a) in which women agreed or strongly agreed with the statement “I expect to give birth to children in future”. Contraceptive preferences were assessed with questions asking the participants preferred method of contraception used before and after diagnosis of HIV.

Data analysis and interpretation of result. Data were collected and analysed over the period of ten months (December 2013 to June 2014) and quantitative were analysed with the Statistical Package for Social Science (SPSS) version 20.

Indices of data measurement. These indices included

- Descriptive analysis of socio-demographic and reproductive characteristics of the participants
- Bivariate analysis of socio-demographic characteristics associated with desire for children in future
- Predictor variables for observed pattern of fertility desire.

Descriptive statistical analysis of quantitative variables using summary measures and categorical variables using frequencies and percentages was undertaken. Bivariate analysis of socio-demographic characteristics and reproductive characteristics associated with desire for children in future were carried out using chi square test and ANOVA to compare means for

continuous variables. Cohen d and Pearson correlation were also calculated. The level of statistical significance (α) for statistical tests was set at .05.

Phase II (Follow-up Semi-structural Interviews)

Participants. In depth interview were conducted with four participants. During the quantitative survey (Phase I), participants were asked if they would be willing to be contacted for a follow-up interview. From the pool of participants consented to be contacted for phase II, only six of them were reachable. However, one moved out of the city and finally four HIV/AIDS positive women showed up for the interview. The participants were from different age categories (30, 36, 40, and 46 years of age at the time of interview), were living in Prince George, more open to talk, easily contactable and available for interviews. In qualitative research, Creswell (2007), advised that the goal is to select a few individuals and conduct in depth interviews in order to explore the full meaning of the phenomenon. In this study, each participant was interviewed for approximately one hour.

Data collection. Data were collected and analysed over the period of five months, from August 2014 to December 2014.

Interview procedure. I as principal researcher conducted all the interviews. The interviews were conducted in English and at the location of the Dr. A.A. Hamour's Clinic. Due to the researcher's limited experience in qualitative research, the researcher conducted a mock interview with an experienced graduate student of UNBC to gain insights on interview techniques. The graduate student was chosen as because he had past experiences to conduct in-depth interview on HIV positive people. Further commonalities include that his supervisor and my committee member was Dr. Tina Fraser. The mock interview was moderated by Dr. Tina Fraser.

Participants were informed that the interview would be confidential and anonymous. Participants were assigned pseudonyms (participant 1, participant 2, participant 3, and

participant 4) and were informed that their names would not be used in the transcription and/or in the report. The researcher did not engage any paid transcriber for transcribing the interviews; transcriptions were done by the principal researcher. However, as it was the initial plan to use a transcriber, a transcriber confidentiality agreement was prepared and, attached (see Appendix G). The participants were assured by the researcher that at no time their identities would be revealed. The use of assigned pseudonyms protected participants' privacy (see letter of information phase two, Appendix D). Additionally, participants were asked for permission to digitally record the interview before proceeding. A letter of information detailing confidentiality, its limitations, and the rights as research participants was read to participants and their signature was attached in the consent form as a proof of their agreement (Appendix D & E).

The data were collected from four participants by in-depth interviews. The aim of using interview was to gain information on the perspectives, understandings and meanings constructed by people regarding the events of their lives (Grbich, 1999). The interviews were conducted using a semi-structured and open ended questionnaire (Appendix F). The participants were offered an interview schedule at time and place convenient to each participant. All four interviewees chose Dr. A.A. Hamour's clinic for the interview site.

Oral recording and research instrument. The interviews were manually and digitally recorded with the written consent of the participants. However, one participant did not provide consent for digital recording and her interview was manually recorded by the researcher. Digital recording was used to reduce the risk of interviewer bias (Hancock, 2002). The use of a digital recorder allowed the interviewer to listen attentively and responds to the interviewee, and eliminating the possibility of being distracted by writing. Further, the recording of the interview ensured that the entire discussion was captured, and provides

accurate and complete data for analysis. This increased the accuracy and validity of the content of the interview.

Questionnaires and transcriptions of these interviews will be stored in my supervisor Dr. Peter MacMillan's office (UNBC office) for five years post defence. This will ensure that the data are not compromised and are kept strictly confidential. Only the researcher and research supervisor have access to these materials.

Procedure. All four interviews were conducted at Dr. A. A. Hamour's clinic. The interviews began with warm-up questions in order to help participants become slowly engaged in the conversation and to "open up". Each participant was given a copy of the questionnaire on hand and was encouraged to answer the questions serially. Although a list of interview questions (see Appendix F) was used, questions that help to clarify responses or probe for a more in-depth response were also asked. Open-ended questions (questions that begin with "what and how") were asked in order to access participants subjective experiences, perceptions, and to assist the researcher to keep a reflective journal. After the interview participants were given an honorarium of \$25, as suggested by CINHS.

Data Analysis. Before any formal analysis of data began, both the visual and digitally recorded interviews were transcribed verbatim and saved on a computer hard drive. The transcription not only included the words spoken by the participants but also any pauses and emotional reaction from participants. This approach to transcription, which attempts to recreate the interview experience, helped in the process of analysis (Seidman, 1991). The transcripts were analyzed by pencil and paper and used thematic data analysis technique. The transcription was only edited for easy reading. The phases of thematic analysis (Braun & Clarke 2006) which includes: familiarization with the data, searching for themes, reviewing themes, defining and naming themes and producing the report was applied to this study. According to Braun & Clarke (2006), thematic analysis technique, incorporated the inductive

approach. “Thematic analysis is a search for themes that emerge as being important to the description of the phenomenon” (Daly, Kellehear, & Gilksman, 1997). Additionally, it is a form of pattern recognition within the data, where merging themes are used for the categorization of the analysis. The analytic process involved moving from description to interpretation, where the significance of the patterns and their meanings and implications will be highlighted (Patton, 1990).

It was originally proposed that a paid transcriber would be hired to transcribe the data gathered in this research. But in order to familiarize myself with the data, I completed all of the transcription myself. Transcribing the data allowed me to fully immerse myself in the language and experiences of the participants. Transcribing the data myself also allowed me to omit identifying information like names and place of residence within Northern British Columbia.

I printed out the hard copy of the transcription and used an iteration cycle to review the data (see Figure 2). I read the transcripts and notes until a sense of the participants’ overall experiences emerged. After familiarizing myself with the data, I began to highlighting the key points with a colour pen and writing notes on the transcripts. Then I identified some early themes where the key points can fit in. I reviewed all potential themes in order to ensure validity of individual themes in relation to the data set. Themes identified through the preliminary review included feelings, emotions, judgmental, sense of belonging, hopelessness, hopefulness, education, services and supports. The themes identified in the first two iterations of the qualitative data analysis were a foundation to refining a deeper understanding (Please see Appendix I for a collation of these early themes). The themes were reviewed until a point when overlap of information began (point of saturation). Further reviews and analysis refined the themes to: initial responses to diagnosis, hopelessness, hopefulness, judgmental attitudes, sense of isolation and making it better (education, services

and supports).

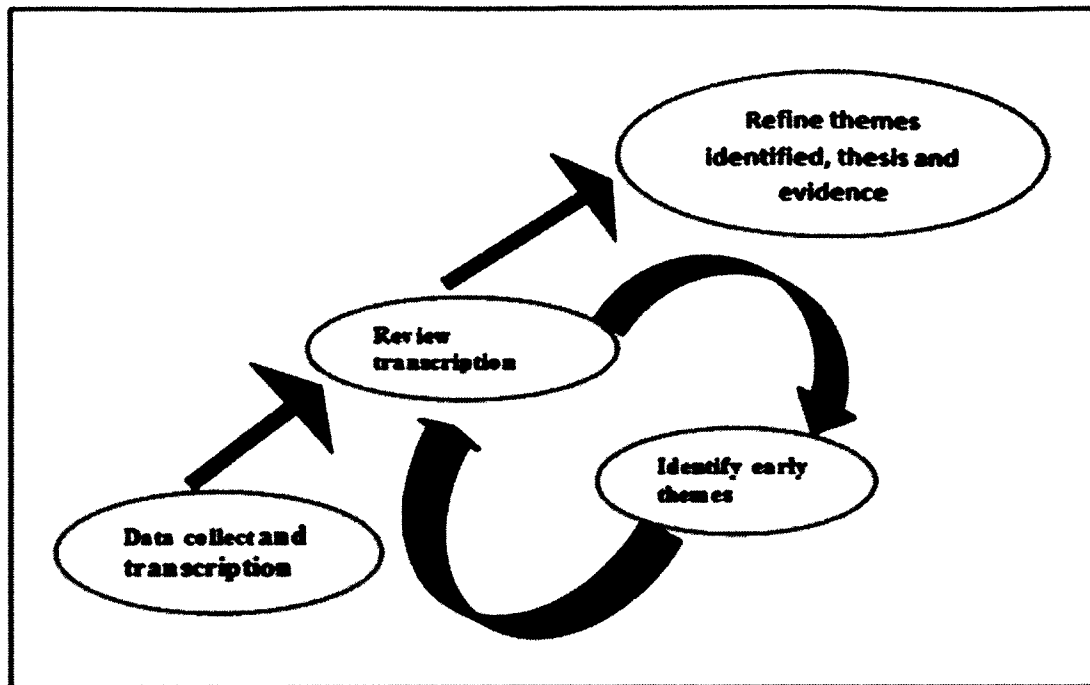


Figure 2. Iteration cycle demonstrating the process of data analysis (Dr. Theresa Healey personal note, 2014)

Organizing, defining and naming themes were challenging. Consulting with my committee members was necessary at this point. The findings of the information of the interviews which include themes revealed through the data analysis will be presented in Chapter Four.

Member (Participant) checking. I gave a copy of each individual transcript to each of my four participants for review and I made follow-up phone calls to confirm the attachments were received. I allotted the participants one week to respond with feedback in regards to the interview transcripts. Only one of the participants reviewed and returned transcripts back to me while the other three participants in this research did not respond to the transcripts provided, so I proceeded with the research under the assumption that no changes were needed.

Ethical Considerations

Approvals from CINHS, the Clinic of Dr. A. A. Hamour, and Northern Health were obtained following UNBC REB approval for the Phase I survey. To conduct the Phase II of the research, separate approval letters from UNBC REB and support letters /permission from Dr. A. A. Hamour were obtained (see Appendix and Appendix L). Informed consent of the study subjects was obtained after explaining the procedure and purpose of the study, ensuring confidentiality and absence of any harm. There was no perceived significant risk to the participants involved with this study as they only responding to some questions without disclosing their identity. This study had no known impact on their healthcare or treatment. However if the participants required any additional support (e. g counselling) they had been provided with contact information for support services provided by the study sites or Community Care Center in Prince George.

Participants' information collected during research has been kept in a locked cabinet in the office of the supervisor Dr. Peter MacMillan (UNBC, 10-4040). The data file with confidential information stored in a pass-word protected computer. The confidential file name coded without confidential information in the file title. The data files are also stored on the double pass-word protected student 'H' drive on the university computer. The data file is only accessible by the principal researcher (Farzana Amin) and to the supervisor Dr. Peter MacMillan. Paper copies (questionnaires and transcriptions of interviews), audio and the data file will be kept for 5 years maximum post-thesis-completion in order to meet peer reviewed journal publication expectations. The paper copies will be shredded, audio and the electronic copy (data file) will be permanently deleted. The findings of this research will be shared with relevant research affiliated parties and the research participants during a luncheon organized by the researcher after a successful thesis defence. Only the summary report will be shared with the organizations Northern Health, CINHS, and clinic of Dr. Abu Hamour, which

granted access to conduct this research. After my thesis defence and the completed thesis will be available at the UNBC library. The information collected from the participants will be used for thesis completion, conference presentation, report, and journal publication without disclosing any details that might reveal their identity.

Adequate emphases were taken by me, as a researcher, to enhance skills prior to communicating effectively with participants and collecting data. This survey targeted the general population within the northern context of Canada; however some of the participants were Aboriginal ethnicity because of geographical location of the study. The research questionnaire and the protocol had been developed carefully considering the cultural safety of the participants. Cultural safety according to Ramsden (2002), a Maori scholar, is beyond cultural awareness and cultural sensitivity. It gives people the power to comment on care and to be involved in changes in where their experiences have been negative. Culture refers to “learned, shared and transmitted value, beliefs, norms, and lifeway’s of a particular group that guides their thinking, decisions, and actions in patterned ways” (Leininger, 1991, p. 47). Therefore, culture is a beginning step toward understanding that there is a difference. As a newcomer to Canada, and engaging with research within the Canadian context, I did approach the participants with the upmost respect. I took a medicine wheel approach, by holistically giving attention to the physical, emotional, spiritual and mental health of the participants that operates within the concept of community health. This study did not compromise the legitimate cultural rights, values and expectation of the research participants.

CHAPTER FOUR: RESULTS

This chapter presents a succinct account of the results (both Phase I and Phase II) obtained in this study and the analytical strategies applied to arrive at the results. In addition, it provides detailed interpretations of the findings obtained.

Phase I (Structural Survey)

Twenty-one women living with HIV voluntarily participated and completed the survey questionnaire. This sample is taken from a maximum of 40 HIV Positive Women in the age range of 15 -49 in Prince George region (personal communication with Dr. A. A. Hamour). Of the potential of 40 known (under treatment with Dr. Hamour) participants, 21 (53%) participated. Stripped data released by Dr. Hamour's office indicated that of these 40, 5 (12.5%) were in the 15-29 group, 20 women (50 %) were found in the 30-39 age group, and 15 (37.5 %) women fell in the 40-49 group. .

Table 1 shows the socio-demographic characteristics of the participants. The mean age of the participants is 37.52, standard deviation 6.24. Participants' ages were collected as numerical data. For the purpose of better illustration and analysis participants' ages were grouped as 15-29 years, 30 to 39 years, 40 to 49 years, and accounted for 9.5%, 52.4% and 38.1 % respectively. The majority of the participants were in their 30s and relatively few were under the age of 30 years. Age demographics of this study closely resemble those of HIV positive women in Prince George, overall, indicating that my sample population was representative of actual population in this one characteristic available to me.

Table 1

Socio-demographic Characteristic of the Participants

Characteristics	n	%
Age group		
15- 29	2	9.5
30-39	11	52.4
40-49	8	38.1

Characteristics (Cont....)	n	%
Ethnicity		
Aboriginal (First Nation / Metis/Inuit)	14	66.7
White / Caucasian (European Ancestry)	7	33.3
Religion		
Christian	12	57.1
Atheist	9	42.9
Education		
Some high school	12	57.1
Completed elementary school	4	19.0
Completed high school	3	14.3
Completed college/ university	1	4.8
Some college/ university	1	4.8
Employment status		
Social assistance	20	95.2
Employment insurances	1	4.8
2013 annual income (before tax)		
Less than 10,000	6	28.6
10,000 – 14,999	14	66.7
More then 15,000	1	4.8
Marital Status		
Married or equivalent	10	47.6
Single	6	28.6
Separated	1	4.8
Divorced	2	9.5
Widowed	2	9.5
Partner HIV Status		
HIV positive	12	57.1
HIV negative	3	14.3
Don't know	4	19.0
Not applicable	2	9.5
Currently Receiving HAART		
Yes	20	95.2
No	1	4.8
Do you have Children		
Yes	18	85.7
No	3	14.3
Number of Children (categorized)		
No children	3	14.3
One children	4	19.0
Two children	11	52.4
> Two children	3	14.3
Age of Last Child (categorized)		
Pre-school	4	22.2
Elementary	7	38.9
Secondary	5	27.8
Post-secondary	2	11.1

Although survey participants could respond with any ethnicity ranging from Aboriginal, White/Caucasian, Hispanic, Black /African to Middle Eastern, the respondents indicated only two groups, Aboriginal and White/Caucasians. Results show two-thirds (66.7%) of the participants were Aboriginal and 33.3% of the participants were White/Caucasian. Aboriginal option included First Nation, Métis, and Inuit. White / Caucasian refers to European ancestry. Participants were given eight options to indicate their religion preferences. Among the Christianity section there were two sub categories (Catholic and Protestant) and one open option “other” to indicate any other affiliations. The general “other” category provided an open option for the participants to indicate whether they were agnostic or atheist or any other preference. High proportions of the participants indicated they were Christian (57.1%) in general without indication any subcategories; indicated and while Atheist constituted 38.1% of the participants.

The majority of the participants had some level of high school education (57.1%) but less than one quarter had ever completed high school or any college/university education. With the exception of one participant who reported to be on EI (employment insurance), 95% of participants were on social assistance so the majority of them had an annual income within \$ 10,000 to \$ 14,999 (before tax). Approximately half of the participants reported themselves as married or in equivalent relationship (47.6%); while 28.6% indicated they were single, never married and only 9.5% described themselves as widowed and divorced.. The majority of respondents reported to have HIV positive partner (57.1%), although 14 % claimed they had HIV negative partner. One fifth of the women claimed not to know their partner HIV status. More than 80% participants reported to have children and majority (66.7%) of them have two or more children.

Descriptive analyses of reproductive characteristics of the respondents are shown on Table 2. Among the respondents 28.1% of the women became pregnant after being diagnosed with HIV and majority of these pregnancies were indicated not to be planned or intended.

Table 2

Reproductive Characteristics of the Participants

Characteristic	n	%
Pregnancy Since Tested HIV Positive		
Yes	6	28.5
No	15	71.4
Pregnancy After Tested HIV Positive were Intended/Planned		
Yes	4	19.0
No	15	71.4
Somewhere planned	2	9.5
Menstruation cycle		
Yes	18	85.7
No	3	14.3
Sexual Intercourse in last six month		
Yes	17	81.0
No	4	19.0
Intend to have Children in Future		
Yes	10	47.6
No	8	38.1
Uncertain	3	14.3
Partner desire pregnancy		
Yes	9	42.9
No	3	14.3
Don't Know	6	28.5
Not Applicable	3	14.3
Birth Control Used Before diagnosis with HIV		
Yes	10	47.6
No	11	52.4
Preferred Method of Birth Control before Diagnosis with HIV		
Male condom	7	70.0
Oral contraceptive	1	10.0
Female sterilization	1	10.0
Injection (Depo-Provera)	1	10.0
Birth Control Used after Diagnosis with HIV		
Yes	11	52.4
No	10	47.6

Cont....

Characteristic	n	%
Preferred Method of Birth Control after		
Diagnosis with HIV		
Male condom	5	45.4
IUD	2	18.1
Female sterilization	4	36.3
Expected to Give Birth in Future		
Strongly agree	2	9.5
Agree	8	38.1
Neither	6	28.6
Disagree	2	9.5
Strongly disagree	3	14.3
More Likely to have Children Than		
Before Diagnosed with HIV		
Strongly agree	4	19.0
Agree	4	19.0
Neither	8	38.1
Disagree	5	23.8
Strongly disagree	0	0.0
How Many Children You Want		
One children	9	42.9
Two children	1	4.8
Don't know	3	14.3
None	8	38.1

Although 47.6% of the participants reported that they were using various contraceptive methods or birth control before being infected with HIV. However after diagnosed with HIV, the proportion of participants using birth control increased minimally to 52.4%. Participants indicated that they mostly preferred to use male condoms both before and after HIV; however the proportion of stated preference to use of male condom decreased from 70 % to 45.4 % after diagnosed with HIV.

During the survey period a high proportion of participants (95.2%) indicated that they were on HIV medication, more than 80 % participants reported they were sexually active within the past six months. The participants were asked about their intention in relation to having children in future; the participants' responses to this were used to quantify their fertility desire in this research. All most half of the respondent (47.6%) indicated that they

desired to have children in future while 38.1% reported they do not want children. About 50% of the respondent reported that their partner also desired to have children.

Twenty one participants expressed their feelings to have children in future by reporting they agreed or strongly agreed to expect with the statement that they will give birth in the future. The level of their feeling were measured on Likert-like scale ranging from 1 to 5, to which respondents disagree or agree (1= strongly agree, 2= agree, 3 = neither, 4 = disagree and 5= strongly disagree). A higher proportion of participants agree or strongly with the statements while a low proportions of women were disagreed (9.5%) and, strongly disagreed (14.3%) with the statement. The majority of the participants (38%) stated that their HIV status influenced their decision to have children, however the other 38 % reported the influence as neutral and 23.8% indicated the opposite view.

Table 3 shows participants' responses indicating why they desire, or not, or were uncertain to have children in future. Participants' responses were coded in groups according to the similarity of the content of texts. (Please see the Appendix H for original responses of the participants). The respondents who desire children in future were driven by the following reasons: experience motherhood and have family (23.8 %), someone to love and care (9.5 %), experiences motherhood and pass the culture (14.3 %). However, a good proportion women (23.8%) who had no desire for children because of their fear to transmit the diseases to their new born.

Table 3

Reasons for Desiring or Not Desiring or Uncertain to have Children

Characteristics	n	(%)
Reasons for desiring children	10	47.6
Experience motherhood and have family	5	23.8
Feel motherhood and pass the culture	2	9.5
Someone to love and care	3	14.3
Reasons for not desiring children	8	38.1
Fear of transmitting the HIV to child	5	23.8
Age	2	9.5
Completed family	1	4.8
Uncertain	3	14.3
Fear of transmitting the HIV to child	2	9.5

The possible associations between the socio-demographic characteristics and fertility desires of the respondents were identified by several Chi-Square tests ($\alpha = .05$). Ethnicities of the respondents were grouped as Aboriginal and White/Caucasian. Among these tests, only one test showed a difference that indicated a statistically significant association between the ethnicity and fertility desire of the participants ($\chi^2 = 5.51$, $df=2$, $p = .05$). The proportion of Aboriginal women who reported that they preferred to have more children in future was 64.4%. This percentage is higher than the percentage of the White Caucasian women (see Table 4). The result of chi-square test can be interpreted as significant; the researcher may take this as a possible Type I error due to a single significant result after 11 statistical tests were performed. However, an application of a more cautious Bonferroni-like approach using $\alpha = 0.01$ to partially contract the false excessive positive rate resulted in a non-significant result from the chi-square test. This application has now created the possibility of this interpretation resulting in a Type II error, which is failing to find a result that actually exists in the population. For this study, I treated the result as significant that is a statistically significant association between the ethnicity and fertility desire of the participants. The results from Chi-Square tests are shown to illustrate the lack of association between the

socio-demographic characteristics and fertility desire of the respondent on Table 4 with the exception between ethnicity and fertility desire of the participants as discussed.

Table 4

Relationship between Socio-demographic Characteristic and Desire for Children

Characteristics	Desire for children						χ^2 Value	p-value
	n	%	Yes n %	No n %	Uncertain n %			
All respondent	21	100	38.1	38.1	23.8			
Age Group						6.41	.17	
15- 29	2	9.5	2 100.0	0 0.0	0 0.0			
30-39	11	52.4	5 45.5	3 27.3	3 27.3			
40-49	8	38.1	3 37.5	5 62.5	0 0.0			
Ethnicity						5.51	.05	
Aboriginal (First Nation / Metis/Inuit)	14	66.7	9 64.3	3 21.4	2 14.3			
White / Caucasian (European Ancestry)	7	33.3	1 14.3	5 71.4	1 14.3			
Religion						2.05	.36	
Christian	12	60.0	7 58.3	3 25.0	2 16.7			
Atheist	8	40.0	3 33.3	5 55.6	1 11.1			
Education						10.83	.21	
Some high school	12	57.1	6 50.0	5 41.7	1 8.3			
Completed elementary School	4	19.0	2 50.0	2 50.0	0 0.0			
Completed high school	3	14.3	2 66.7	0 0.0	1 33.3			
Completed college/ University	1	4.8	0 0.0	1 100.0	0 0.0			
Some college/ university	1	4.8	0 0.0	0 0.0	1 100.0			
2013 annual income (before tax)						3.45	.48	
Less than 10,000	6	28.6	4 66.7	2 33.3	0 0.0			
10,000 – 14,999	14	66.7	5 35.7	6 42.9	3 21.4			
More then 15,000	1	4.8	1 100.0	0 0.0	0 0.0			
Marital Status	21	100				12.1	.144	
Married or equivalent	10	47.6	7 70.0	2 20.0	1 10.0			
Single	6	28.6	2 33.3	3 50.0	1 16.7			
Separated	1	4.8	0 0.0	0 0.0	1 4.8			
Divorced	2	9.5	0 0.0	2 100.0	0 0.0			
Widowed	2	9.5	1 50.0	1 50.0	0 0.0			
Partner HIV Status	21	100				7.4	.28	
HIV positive	12	57.1	6 50.0	5 41.7	1 8.3			
HIV negative	3	14.3	2 66.7	0 0.0	1 33.3			
Don't know	4	19.0	1 25.0	3 75.0	0 0.0			
Not applicable	2	9.5	1 50.0	0 0.0	1 50.0			

Characteristics Cont....	Desire for children				χ^2 Value	p-value
	n %	Yes n %	No n %	Uncertain n %		
Receiving HAART	21 100				1.5	.56
Yes	20 95.2	9 45.0	8 40.0	3 15.0		
No	1 4.8	1 100.0	0 0.0	0 0.0		
Do you have Children	21 100				3.8	.14
Yes	18 85.7	7 38.9	8 44.4	3 16.7		
No	3 14.3	3 100.0	0 0.0	0 0.0		
Number of Children (categorized)	21 100				9.4	.15
No children	3 14.3	3 100.0	0 0.0	0 0.0		
One children	4 19.0	1 25.0	1 25.0	2 50.0		
Two children	11 52.4	4 36.4	6 54.5	1 9.1		
> Two children	3 14.3	2 66.7	1 33.3	0 0.0		
Age of Last Child	18 100				8.2	.22
Pre-school	4 22.2	2 50.0	0 0.0	2 50.0		
Elementary	7 38.9	3 42.9	3 42.9	1 14.3		
Secondary	5 27.8	2 40.0	3 60.0	0 0.0		
Post-secondary	2 11.1	0 0.0	2 100.0	0 0.0		

A number of Chi-Square tests ($\alpha = .05$) were performed to detect the association between fertility desire and the reproductive characteristics of the respondent. The results are presented on Table 5. A statistically significant difference was found between the respondent's partner's preference to have children and the respondent's fertility desire ($\chi^2 = 23.9$, $df = 2$, $p = .001$). A high proportion of respondents (88.9%) whose partners preferred to have child indicated that they desired to children in future.

Table 5

Relationship between Reproductive Characteristic and Desire for Children

Characteristics	Desire for children						p-value
	n	%	Yes n %	No n	%	Uncertain n %	
All respondent	21	100	38.1	38.1		23.8	
Menstruation cycle							
Yes	18	85.7	9 50.0	6 33.3		3 16.7	1.4
No	3	14.3	1 33.3	2 66.7		0 0.0	.49
							23.9
Your Partner desire pregnancy							
Yes	9	81.0	8 88.9	0 0.0		1 11.1	
No	3	14.3	0 0.0	3 100.0		0 0.0	
Don't Know	6	28.7	1 16.7	5 83.3		0 0.0	
Not Applicable	3	14.3	1 33.3	0 0.0		2 66.7	
Birth Control Used before Diagnosis with HIV							1.2
Yes	10	47.6	4 40.0	5 50.0		1 10.0	.55
No	11	52.4	6 54.5	3 27.3		2 18.2	
Birth Control Used after Diagnosis with HIV							3.9
Yes	11	52.4	3 27.3	6 54.5		2 18.2	.14
No	10	47.6	7 70.3	2 20.0		1 10.0	
Had sexual intercourse in last 6 month							.89
Yes	17	81.0	8 47.1	6 35.3		3 17.6	.63
No	4	19.0	2 50.0	2 50.0		0 0.0	
Expected to Give Birth in Future							27.56
Agree (strongly agreed and agreed)	10	47.6	10 100.0	0 0.0		0 0.0	.00
Neither	6	28.6	0 0.0	3 50.0		3 50.0	
Disagree (strongly disagreed and disagreed)	5	23.8	0 0.0	5 100.0		0 0.0	
More Likely to have Children Than Before Diagnosed with HIV							9.42
Agree (strongly agreed and agreed)	8	38.1	6 75.0	1 12.5		1 12.5	.05
Neither	8	38.1	4 50.0	4 50.0		0 0.0	
Disagree (strongly disagreed and disagreed)	5	23.8	0 0.0	3 60.3		2 40.0	

A statistically significant association was found between the fertility desire of the respondents and their opinion on probability to give birth in future ($\chi^2 = 27.56$, $df = 4$, $p < .005$) and similarly between the respondent's HIV status and their fertility desire ($\chi^2 = 9.42$, $df = 4$, $p = .05$) (see Table 5). The researcher may take this result as a possible Type I error due to a single significant result after 7 statistical tests were performed. However, a more cautious Bonferroni-like approach using $\alpha = 0.01$ to partially contract the false excessive positive rate resulted in a non-significant association between the fertility desire of the respondents and their opinion on probability to give birth in future. This application has again created the possibility of this interpretation resulting in a Type II error, which is failing to find a result that actually exists in the population. For this study I have considered the result as significant. Among the 8 (38.1%) participants who agreed with the statement that their HIV status influenced them, 75.0 % indicated to desire children in future, however, among 23.8% of women who disagreed with the statement 5 point scale, item 22 and item 13 (on the yes/ no / uncertain), 60% reported they did not desire to have children in future. A Chi-Square test revealed that there was no statistically significant association between the participant's ethnic group and their religious belief ($\chi^2 = .037$, $df = 1$, $p = .60$). This indicated that participants' religious belief and ethnicity are quite independent and religion was not confused with the ethnicity in the standard.

We have tested homogeneity of variances (Levene test) for two variables the age of the respondent and the age of their youngest child against the fertility intention factor (on the yes / no / uncertain, item 13). The Levene test revealed that there were no statistical significant differences ($p > .05$) among the variances of the groups and therefore one factor ANOVAs were conducted. Table 7 and Table 6 show the ANOVA results.

Table 6

One Factor ANOVA for Age of the Participants Against the Participants Response to Fertility Intention

Age of Participants and Response to Fertility Intention	<i>n</i>	Mean (<i>M</i>)	Standard Deviation (<i>SD</i>)	Mean Square (Between Groups) <i>M_{sb}</i>	Mean Square (Within Groups) <i>M_{sw}</i>	<i>F</i>	<i>P</i>
Yes	10	35.1	5.4	131.8	28.6	4.6	.02
No	8	42.0	5.8				
Uncertain	3	33.6	2.9				

The age of participants that responded ‘No’ had the highest mean age and standard deviation ($M = 42.0$, $SD = 5.8$) and the age of the participants that responded “Uncertain” had the lowest mean age and standard deviation ($M = 33.6$, $SD = 2.9$). One factor ANOVA revealed that there was a statistically significant difference between the mean age of respondents and their fertility intention $F(2, 18) = 4.60$, $p = .02$. Post Hoc comparison using LSD indicated that there were statistically significant difference between the mean age of “No” responders and, the mean age of “Uncertain” and “Yes” responders group ($p = .03$ and $p = .01$). This may be due to the fact that “No” responders as a group were older ($M = 42$). However, Post Hoc comparison using LSD revealed that there was no statistically significant difference between the mean age of “Yes” responders and “Uncertain” responders ($p = .69$).

The practical significance of Post Hoc LSD results was tested using Cohen’s *d*. The Cohen’s *d* test was calculated using the Mean Square (within groups) as the denominator and indicated that the result had large practical significance ($d = 4.1$).

Table 7

One Factor ANOVA for Participant's Youngest Child Age and Participants Response to Fertility Intention

Age of Participants Youngest child Response to Fertility Intention	n	Mean (<i>M</i>)	Standard Deviation (<i>SD</i>)	Mean Square (Between Groups) <i>M</i> _{sb}	Mean Square (Within Groups) <i>M</i> _{sw}	F	P
Yes	10	6.7	6.3				
No	8	13.0	5.0	144.8	32.8	4.4	.03
Uncertain	3	4.6	4.7				

The age of youngest child of the participants that responded 'No' had the highest mean ($M = 13.0$, $SD = 5.0$) and the age of youngest child of the participants that responded "Uncertain" had the lowest mean ($M = 4.6$, $SD = 4.7$).

One factor ANOVA revealed that there was a statistically significant difference between the mean age of participant's youngest child and the participants fertility intention $F(2, 18) = 4.41$, $p = .028$. Post Hoc comparison using LSD indicated that there were statistically significant differences between the mean age of the youngest child of the participants who responded "No" and the mean age of the youngest child of the participants who responded "Yes" and "Uncertain" ($p = .02$ and $p = .03$). This may be due to the fact that "No" responders as a group had older youngest child ($M = 13$). However, Post Hoc comparison using LSD revealed that there was no statistically significant difference between the mean age of the youngest child of the participants who responded "Yes" and those who responded "Uncertain" ($p = .60$).

The practical significance of Post Hoc LSD result was tested using Cohen's d . The Cohen's d test was calculated using the Mean Square (within groups) as the denominator and indicated that the result had high practical significance ($d = 7.5$).

The Pearson correlation indicated that there was a positive correlation between the age of the participants and the participants youngest child age ($r = .74$, $df = 19$, $p < .005$). This positive correlation can be seen in the scatter plot where the older participants had older youngest child (see Figure 2). A positive relationship is expected as it is difficult for many younger women to have older children.

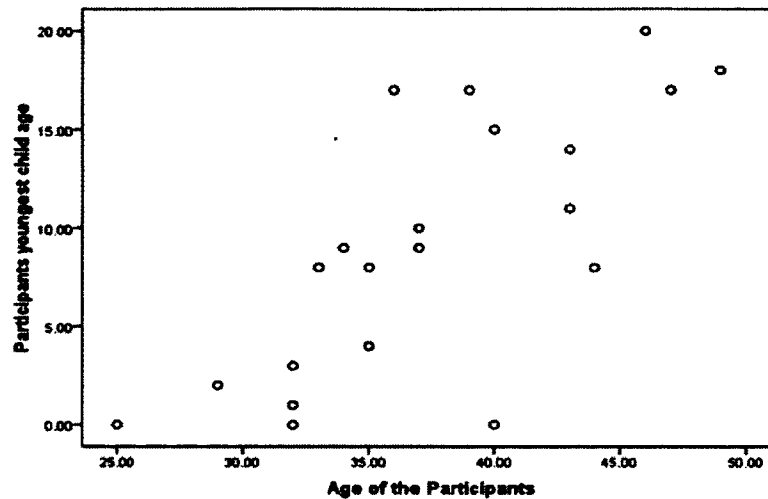


Figure 3. Relationship between the ages of the participants and the ages of the participant's youngest child.

Summary of Results for Phase I

Majority of the participants (52.4 %) were within the age group of 30- 39 years and 66.7% participant was of Aboriginal ethnicity. Half of the participants (47.6%) reported desire to have children in future. A high proportion of women (80%) reported to be sexually active and their preferences for the use of male condom reduced after diagnosis of the HIV. Result revealed that there are four characteristics significantly related with the fertility desire of the women and these are

- Ethnic background: Women who were of Aboriginal origin desire more children than that of Caucasian background ($\chi^2 = 5.51$, $df = 2$, $p = .05$)
- HIV positive status of women ($\chi^2 = 9.42$, $df = 4$, $p = .05$)

- Preference to give birth in future ($\chi^2 = 27.56$, $df = 4$, $p = .005$)
- Partner preference to have children ($\chi^2 = 23.9$, $df = 2$, $p = .001$)

One factor ANOVA detected that Women who were in 30s preferred to have more children in future than the women who were in their 40s, $F(2, 18) = 4.60$, $p = .024$ and the result had large practical significance ($d = 4.1$). There were also significant difference between the mean age of the participant's youngest child and their fertility intention $F(2, 18) = 4.41$, $p = .03$). Women who had youngest child aged seven years or less preferred more children in future and result had high practical significant ($d = 7.5$).

The key reasons women mentioned to desire children in future were to experience motherhood and to pass their culture and, the reasons women stated not to desire children was the fear of vertical transmission of the infection.

Phase II (Follow-up Semi-structural Interviews)

This phase examined HIV positive women's experiences through an in-depth face to face semi-structured interviews in regard to their desire to have children or not to have children, their experiences regarding their own and other HIV positive women's fertility issues, their opinions about the available supports and services in Northern British Columbia. The guiding used for the interview has given in Appendix F while the raw data are reported in Appendix I. This section outlines the results of four qualitative interviews. Questions were asked in order to gain knowledge and understanding of their stories and insights, as well as to acquire information about the challenges HIV positive women face for the fertility. The research findings are based on direct quotes from the qualitative interviews so as to appropriately reflect the experiences of the participants.

Interviews were conducted with four participants at Dr. A. A. Hamour's clinic over a one week period. Participants were aged: 30 (participant 1), 36 (participant 2), 40 (participant 3), and 46 (participant 4) years old. Among the four participants, three were Aboriginal and

one participant was Caucasian. Two participants (participant 1 and 2) specified during the Phase I interview that they would like to have children in the future, whereas participants 3 and 4 indicated that they did not want have any children in the future. The two who indicated a desire to have more children are in their 30s while the two who indicated no desire were in their 40s.

Three of the participants mentioned that they had children prior to their HIV diagnosis, however none raised their children. A thematic analysis of the interview data revealed six themes and key findings from the qualitative research were reported under these themes which are

- Initial responses to diagnosis
- Hopelessness
- Judgmental attitudes
- Sense of belonging
- Hopefulness
- Making it better

Findings of the interviews and themes are discussed below. To accurately represent the experiences of the participants, quotes were used even in cases of longer responses. As well, the use of tables was avoided.

Initial responses to diagnosis. The initial reactions of women revealed deep and powerful feelings. As one woman said *“it was the most horrible day of my life.”* Another said: *“I wanted to kill myself, try to jump out of the building. I was crying like hell. It felt devastating. I felt like I was drowning in a very cold sea.”*

Many of these powerful feelings are related to the effort to accept and understand what has happened. Rejecting, denying, being unable to accept the diagnosis seems to be a

very common initial reaction. One participant noted she *“still cannot accept”* the reality of the diagnosis. Others spoke to *“having to accept it.”*

In this stage, women also recognized how the diagnosis shifted their sense of self-identity. As HIV positive, a woman becomes *“dirty, not normal, a burden to the health care system and the government.”* Another woman noted: *“I became a dirty junky woman with just one phrase: ‘I’m HIV positive.’”* This shift in identity also reflects a shift in their perceived position in the world. HIV positive women have to think differently and move differently in the world. *“If a woman is not HIV positive she doesn’t have to fear that she will be hated by others.”* Another said: *“I feel like I am not welcome anywhere, nobody wants me.”*

The impact of the diagnosis is quickly related to the questions of pregnancy. The decisions and choices become painful in this stage. One woman noted: *“I had an abortion. I was horrified at the thought of having to have a HIV positive baby.”* Another comment showed how quickly women decided not to have children: *“I don’t want to have the guilt of having a baby and then letting them him or her be HIV positive.”*

Hopelessness. The participants indicated that living with the HIV positive status is an emotional and sensitive experience (e.g., they were frustrated about life). One of the participants said: *“HIV took everything from me”*, other commented *“I thought my life was over and I had no future at all.”*

As a result of the attitude of other people towards these women, the majority of them felt isolation and the neglect from the society including their family and friends. One participant commented: *“No one wants to be friends with me”*, another participant stated: *“If you are HIV positive you belong to different group of people.”* They were stressed about their HIV status and not been able to socialise freely. One woman said: *“If you are HIV positive*

things are different.” Another noted, “HIV positive women have to deal with lots of stress and stigma. I can’t socialize as freely as I could before I was diagnosed with HIV.”

The majority of the women stated HIV positive status influenced their desire to have children and experience motherhood like others who are not HIV positive. They were restricted by their HIV status to make their choices about life. The women appeared uncomfortable to talk or discuss their fertility desire with their health care provider. Some participants reported that they had lost trust and felt hopeless to be become a mother at certain point of their life *“When HIV positive women want to have a baby, they can’t talk about it easily. They have to be careful not to pass the infection to their baby”* Another woman noted: *“Knowing that I am HIV positive I didn’t keep the baby. I did an abortion. Even though the Doctor told me it might not go to my baby but I didn’t trust. I thought they were just saying it because I was already four months pregnant.”*

The participants recognized that their HIV diagnosis obliged them to carefully plan for their future. *“Wanting children when I was not HIV positive and now when I am HIV positive there are lots of differences.”* Women discussed the impact of HIV on their financial stability. HIV contributed to their poor health, making it difficult for them to work. Poor health and poor financial conditions influenced women to decide to have or not to have children. The thought of feeding options for their children was a source of great concern because most of the participants don’t have financial affluence and they neither could afford to buy baby formulae nor manage to exclusively breastfeed their babies. One women noted *“I won’t able to breast feed my baby. I will have to buy formula food which is expensive. I need money.”* Another commented *“It is difficult to raise children for HIV positive women compare to the women who are not HIV positive because they don’t have to face difficulties to find a job.”*

Some participants mentioned that they were not provided with enough information early about the pregnancy and HIV status. They do not desire to have children possibly because of perceived health risks during and after child birth. There is an observed inverse relationship between the age of the women and their fertility desires. It appeared that women in their 40s loses their interest for having a child. One woman in her 40s mentioned *“I wanted to have a baby, to have someone to love. It’s too late [to have children]. If someone had told me earlier [i.e. in her 30s, at the early stage of HIV diagnosis] I could have a healthy baby, I could surely have one [baby]. Another commented “I am 46 year and not in good health. Now it is not important for me to have child at this age.”*

Judgmental attitudes. The women mentioned that they were scared, nervous and feared rebuff *“There is shame you are HIV positive, just deal with your own problems why do you want to bring another one. There is lots of stigma”*. Some women indicated that the health care provider had never had a proper conversation specifically on fertility preferences *“No one told me I could have a healthy baby without HIV, I was young when I was diagnosed with HIV, they (health care provider) should have thought that I would want to have a baby”*. However, the majority of the women felt that health care providers were judgmental about the use of contraceptives without being aware of their fertility desires.

“They (nurses and doctors) all the time were telling me to take medicine ...use condom, not to infect others with HIV, and not to get infected with other infectious diseases. They all talk about contraceptive...tighten tube... no one ever asked “hey do you want family, do you want to have baby? There was no one to talk to.....No one ever asked me this question.” Interview # 1

The majority of the participants stated that pregnancy related information was not provided to them at the onset of their HIV management. Some participants indicated they were not aware that they could give birth to HIV negative babies at the beginning of their

diagnosis. As one woman commented *"I had no clue whether I could have a healthy child."* Another noted *"HIV positive women need to be open, have to ask otherwise no one would tell them about the information they are looking for."*

Participants reported they felt discriminated and lack of empathy for the range of health professionals. As one women noted *"Nurses were not so happy, were not excited. I am sure nurses will be more supportive if women who are not HIV positive and wanted their help or wanted to have child."* Other commented

"They (doctor /nurse) were not happy; I saw that, I read it in their faces."

"No doctor or nurse will encourage you to have a baby. They won't help me, I knew, no need to ask."

Sense of belonging. Women spoke of a sense of belonging around anticipated pregnancy, which was linked to the belief of motherhood as natural feminine responsibility. One woman said *"Women are born to be mother, taking care of family."* Another mentioned *"I am a young woman.... it is natural that I would like to be a mother."*

This theme reflects the women feelings about their right to have children despite of their HIV positive status. It seemed that women status as HIV positive should not be seen as an automatic reason to discount fertility. *"It's not about HIV positive or HIV negative status, it's about the women ...usually they want to have a child. It's kind of natural thing."* It has been observed that the women have a strong desire for childbearing, which were related to sense of care, love and affections *"I think I won't be lonely like now if I would have one child. It is important to have baby especially if a woman want to have one (baby) ...if you are lonely like me... it is very important to have someone to love."*

Hopefulness. Many participants overcome the fear surrounding their fertility desire and they are able to bridge the subjects (fertility desire) and look hopefully towards a better future *"I think that [baby] could give us [HIV positive women] hope to live healthy.... Inspire*

us to live. HIV positive women could be a good mother like others .You can have HIV free baby if you live healthy, take medication.” Another woman commented: “Want to have a family ... I do want to have a child and a normal life like other women.”

It appears that HIV infection weakens the women both mentally and physically, however it does not eliminate their fertility desire. A woman said: *“My partner and I did lots of research through internet and we talked regularly.... asked my doctors about my pregnancy....yeah if I want I can have a healthy baby.”* Another noted: *“I always wanted to have a child. I want to get pregnant ... I want to take another chance. My partner wants it too.”*

This theme shed light on how acquired knowledge impacts on HIV positive women's self-confidence. Gaining knowledge on HIV/AIDS empowered some participants thinking positively and being hopeful about life, and considering them as good as other women who are not HIV positive. One participant said *“They (HIV positive women) have a future, they are not alone. There are whole world out their....lots of things going on. Our friends and families need to support us to be open and live healthy. Another commented “We can also have children and families and have normal lives like others. If anyone wants to have a child, HIV shouldn't be a problem for having a healthy baby. They should go for it....it is their choice.”*

Making it better. This theme describes HIV positive women's insights on how to better support HIV positive women around issues of fertility, pregnancy, and motherhood. This theme had two strong sub themes: Education and Services/supports.

Education. Women living with HIV experiences difficulties to deal with their daily life. They felt if their families and friends are educated about HIV it may reflect a stronger relationship between them and reduces stigma about their fertility desire. It may also increase intimacy and trust in their family relationship.

"At first, my sister would not let me touch her baby. She would not let me play with her babies. I told her, 'It's okay.' You cannot get HIV through touch. But she still does not want me around them." Interview # 4

One woman said *"We need information and education for family and friend to have their support. They have to understand I can be a mother."* Another commented: *"It is necessary to provide counselling to our family and friends... we need more information and more activity to reduce stigma about HIV and pregnancy."*

"There is another woman in my house going through the same stages of denial I went through. She overheard me talking openly with others about my HIV. She came to me and cried and asked 'how can you be so open about HIV?' I talked with her and now I see how she has accepted her situation and how open she is now. Help us to be open and live healthy lives." Interview #2

Participants commented there is still need for adequate education regarding HIV. The women felt education will increase awareness and perception about HIV in the community and this will increase the disclosure of their HIV status among their family and friends, and help them to live normal lives, and may help them to accomplish their fertility desire.

Service/Support. Interviews revealed that most women wanted their health care provider to initiate discussions and show interest in their fertility related issues. Health care workers usually ask HIV positive women to use contraceptives but the women who have the desire to have children preferred to have open discussion and encouragement about their fertility desire and contraceptive uses.

Some women who desire and intend to have children could not initiate these conversations with their healthcare providers due to the perceived stigma associated with childbearing among the HIV positive women. However, women mentioned that they were more likely to initiate these discussions with their healthcare provider when the provider asks

specific questions about their childbearing desires and intentions. For many participants, health care providers who initiated such discussions enabled them to be open and talk freely and feel like other women who are not HIV positive. One woman noted *“the doctor and nurse should ask the question whether they want a baby not and have the conversation with comforting voice and happy face (doctors/ nurses), assurance for help and help them to be more open and ask questions.”* Another noted: *“We need to be able to talk freely with the doctor/nurse Need to be treated as other women who don't have HIV and wants to have child.”*

Women mentioned they would preferred to have a HIV clinic providing all the services related to childbearing issues in Prince George city to ease the transportation cost, and stress. Traveling to other city for medical support causes the women to suffer emotional separation from their families and friends *“We need to go to Vancouver for that we need money, emotional and physical support”*. The women also mentioned that there should be more job opportunity for HIV positive people so that they could have financial stability to support themselves and their families. Furthermore, the women noted that they prefer to have day care centers for HIV positive babies with adequate and specialized care and also prefer to have an HIV positive women's groups where they can share their experiences and thought of being HIV positive and intents to have child/children *“We need to develop an HIV positive woman group (who are pregnant and who wants to become pregnant, who already have children and young HIV positive women) to share our thought and experiences.”*

Key Findings of Phase II

At the initial stage of HIV diagnoses all the women reported to be shocked with their HIV status, they were in denial, anger and grief. However, over time the women gradually accepted the situation, but many had the fear and guilt to be responsible to transmit the diseases and have HIV positive baby. This finding is supported by the result of Phase I where

women reported the main reason not to desire or uncertain to have children in future was the fear of vertical transmission of the infection.

Women reported that their fertility desire was influenced by the community stigma, and health-related factors including providers care. Age influences the women fertility desire. Women younger than 40 years have more fertility desire compared to older women. This finding corroborates the result of the Phase I survey. Women stated that their fertility desire was influenced by their health care providers' attitudes towards their HIV status. They reported to be felt less empathy from their care provider. They detailed that reproductive health care support for the women living with HIV was affected by the power-cantered relationship between the health care providers and the client. Results showed women's reproductive desires were sometimes assumed by their care provider without exploring their individual fertility needs and goals.

The following key suggestions were indicated by the participants to improve their health and accomplish their fertility desire

- There is need for an adequate education regarding HIV in the community to increase awareness and perception about HIV. From participants' viewpoint, it is important to improve awareness with special focus around the HIV related stigma and fertility issues at the community level in northern region
- Health care system in Prince George will benefit from strengthening to adequately support women living with HIV to achieve their fertility goal and desire in Northern British Columbia. They suggested for improvement in counselling regarding fertility issues and HIV status and provision of appropriate information delivered at the point of HIV diagnosis. They proposed to have people-centred services addressing the individual needs in a timely and friendly manner. The availability of full package of reproductive health care services in Prince George will alleviate their challenges

including financial, emotional and physical loss associated with traveling due to referral.

- Establishing of support groups for the women living with HIV in Prince George will provide them an opportunity for peer social and psychological support which may improve overall wellbeing including reproductive health.

CHAPTER FIVE: DISCUSSION

In this chapter, detailed interpretations of the findings obtained from the research, and the relationship of the findings with existing or current body of knowledge are discussed.

Phase I (Structural Survey)

This study is the first of their kind carried out in Prince George. In this phase, I looked at the socio-demographic characteristic of the participants and also the reproductive characteristic of the participants. It is here that I explored the relationship between these two characteristics with the participant's desire for one or more and/or no children at all.

The result of this research revealed that 38.1 % of the sampled HIV positive women living in Prince George intended to have children in future. It showed that many women living with HIV in the north consider the possibility of parenthood. A survey on general Canadian female population of reproductive age reported 37.5% women intended to have children in future and another survey conducted on 2007 on the HIV positive women of British Columbia reported 30% of the women with HIV intend to have children (Ogilvie et al., 2007; Payne, 2004). This suggests that HIV positive women living in north have similar aspiration regarding future pregnancies as other women with HIV and in addition to those HIV negative Canadian women.

This study showed sampled Aboriginal women living with HIV reported to desire more children than their non-Aboriginal counterparts; this generally corroborate a pattern reported in other similar studies (Loutfy et al., 2009). The majority of the participants (67%) in this study were of Aboriginal descent. An analysis of the data revealed that 64.4 % Aboriginal women prefer to have more children in comparison to 33.3% white Caucasian women. This is somewhat expected as Aboriginal women in Canada have higher fertility rate than non-Aboriginal women. Furthermore, Aboriginal populations in Canada are younger than that of overall Canadian population and which is one of the reasons of higher rate of

reproduction among the Aboriginal women (Government of Canada, 2015). In addition, research has indicated that Aboriginal/Indigenous population usually have larger families in comparison to non-Aboriginal population as they believe that larger family offers much personal and emotional fulfilment (Aadnc-aandc.gc.ca, 2015). However, Ogilvie et.al (2007) found that there were no differences between the ethnic background of HIV positive women and their fertility desire. Ogilvie et.al (2007) recruited 47% of Aboriginal women and reported most of Aboriginal participants had achieved their personal fertility goals during the enrolment in the study. The difference of association of ethnicity and fertility desire found in this study and Ogilvie et.al (2007) is possibly due to difference in characteristics of sample population. Though, in this study, I did not specifically consider Aboriginal women because of the small sample size, however the majority of the sample were Aboriginal women. It is to be noted that there is a higher percentage of Aboriginal people residing in Northern British Columbia (15.6%) in comparison to British Columbia as a whole (Vogel, 2011). The vast majority of the Aboriginal people in Northern British Columbia are likely to be of First Nation descent.

The result of this study showed a connection between participants' age and the participants desire to have children in future; women in their 30's desire to have children in future more than the women in their 40s. This finding is similar to the finding of other methodologically diverse studies which indicate that young HIV-infected women experience significantly more fertility desire than HIV-infected older women (Craft et al., 2007; Loutfy et al., 2009). HIV positive women with risk factors such as, drug use and poverty may experience early menopausal symptom in their 40s and this could be a reason of expressed decreased desire to have children. Women may also suffer from chronic stress related to HIV which can cause worsened psychological conditions and can affect their fertility desire (Santoro, Fan, Maslow & Schoenbaum, 2009). Older women express decreased fertility

desire possibly indicating that they might have already reached their desired fertility goal or they may be accepting of what they see as a lack of possibility. This study also found that the younger the age of the participant's youngest child, the more the women desired to have children in future. This positive relationship was expected as it is difficult for many younger women to have older children.

This study determines that there is no association between participant's formal education and their intent to have children in future. The sample group in this study have generally reported lower educational levels. Lack of variation of educational level of my sample may be the cause of inability to find that relationship. However, the above-mentioned finding of this study could recognize the fact that the information related to HIV provided to the different Canadian community is the same for all the society. Similar findings were also reported in a study conducted in Canada in 2007 (Ogilvie et al., 2007). In contrast, a study in Africa (Heard et al., 2007) revealed that obtaining formal education was significantly associated with fertility desire among the people living with HIV (PLWH). This observed difference could be the result of factors such as the sample characteristics, different geographical location, different cultural and socioeconomic conditions of the participants and research method. This study also indicated that there is no association between the women's annual income and their desire to have children in future and this is consistent with the finding of the other study conducted in Canada (Loutfy et al., 2009). However, a study conducted in one developing country, Uganda revealed differences between annual income and fertility desire of PLWH (Heys, Kipp, Jhangri, Alibhai & Rubaale, 2009). Although, this study showed no relationship, it is an expected fact that people living with HIV who have higher education and high income level have more desire to have children (Alemayehu, & Aregay 2012; Heard et al., 2007; Heys et al., 2009; Wekesa & Coast, 2014). All the participants of this study were on government assistance and not highly educated. I believe

my sample produced a negative bias between the income and fertility desire and also between education level and fertility desire. The inconsistent finding between developing and developed countries warranted further studies to explore association between income, education and fertility desire among the people living with HIV.

One of a few points to note are: in this study, I found no association between religious beliefs, employment, marital status, partners HIV status, number of children, and participants receiving HIV medication (HAART) and fertility desire. However, several other studies have found consistent association between the participant religious beliefs, number of children, marital status, current antiretroviral therapy, partners HIV status and fertility desire. However, those studies used different methodologies, predictors as factor influencing fertility intentions (for example participants age at time of HIV diagnosis, self-reports of health status, cultural background) and populations (Alemayehu & Aregay, 2012; Craft et al., 2007; Bedimo-Rung, Clark, Dumestre, Rice & Kissinger, 2005; Ogilvie et al., 2007).

In this research, predictors for reproductive characteristics were, having menstrual cycle, partner desire for pregnancy, use of birth control before and after diagnosis with HIV, involvement in sexual intercourse in last 6 month, expectation to give birth in future and likelihood to have children after diagnosed with HIV. Consistent with the prior research, this study shows that HIV positive status of women as well as their partner's preference to have a child has significant role in their fertility desire (Cooper et al., 2007; Sofolahan & Airhihenbuwa, 2012). Research evidence in many African societies (Uganda and South Africa), indicated that the HIV positive male have more desire to have children than women (Matthews et al., 2011; Myer et al., 2007; Nakayiwa et al., 2006). However, a study conducted in United States reported that desire for children is similar in both men and women (Chen et al., 2001). Further research is recommended to explore this issue in detail in the context of northern community. As like the fact that women in many other societies, the

participants of this study commented (in Phase II) that ability to reproduce is one of the defined identities of women (Dyer, Abrahams, Hoffman & van der Spuy, 2002; Laher et al., 2009; Matthews et al., 2011). The major reasons women reported frequently to have a desire for more children in future despite of the diagnosis of HIV includes expectation to have family and experience the normal life, to feel the motherhood and carry the culture and to have someone to love. On the other hand, 38% of the women who did not want children were afraid of transmitting the HIV to their new born, and this correlates with finding of other research (Withers et al., 2013). Evidence shows that the adherence to HAART reduces the vertical transmission to as low as 1 % (Bitnun et al., 2014). This indicates a need of further intervention to improve the knowledge of HIV e.g. to improve available information and increase the awareness will be helpful in supporting the women to make informed decisions.

There was no association found between birth control preferences before and after diagnosis of HIV and the women's fertility desire. It should be emphasized that the use of male contraceptive was most preferable method both before and after HIV diagnosis; however, participants' preference for the male condom has reduced after their HIV diagnosis. This method of contraception is useful not only preventing the pregnancy but also to inhibit the transmission of HIV and other Sexually Transmitted Infections (STI). Therefore, it is suggested that the healthcare provider should take it under consideration in family planning counselling. Education is required to increase awareness of using barrier methods as this method of contraception is useful not only in prevention of pregnancy but also in inhibition of transmission of HIV and other Sexually Transmitted Infections (STI). Further research is recommended to explore this issue more broadly.

Phase II (Follow-up Semi-structural Interviews)

During the second phase of this research, I interviewed four participants to get a more

in-depth understanding of the women's experiences and knowledge about their fertility issues. The participants were able to disclose some of their challenges in childbearing (to have or not to have children). Most discussions were based in the participants' feeling of inadequacy, hopelessness, sense of belonging, judgmental and hopefulness. It is also based on participants' comments and recommendations as to what would improve their lives. In this discussion, the participants talked about their health care provider and family supports, community education and finding better ways to support HIV positive women around the issues of fertility, pregnancy and motherhood.

Consistent with the finding of other studies, this research showed that initial response to HIV diagnosis resulted in the feeling of incompleteness, and this was related to impact and understanding of the nature of the diseases. The outcome of these impacts may include stigma, suicidal thoughts, denial, depression, anxiety, fear of disclosure of their HIV status, and shame are associated with this incurable chronic diseases (Rao, Pryor, Gaddist & Mayer, 2007; Bravo et al., 2010).

Similar to other literature, this study showed that over the period of time, after acquiring information and knowledge on HIV infection, women felt more confident in their ability to have healthy child and were much more likely to want children (Matthews et al., 2011; Withers et al., 2013). Comparable with other studies undertaken in Kenya, Uganda and South Africa, participants of this study reported that their health care providers advised them to use family planning methods without exploring their fertility goals (Matthews et al., 2011; Myer et al., 2007; Nakayiwa et al., 2006; Withers et al., 2013). Our results are consistent with studies of Sub Saharan Africa women (Matthews et al., 2011; Withers et al., 2013). They pointed out that the fertility desires of women are very powerful despite the fact of their HIV infection. This was due to societal and cultural expectations, as well as their natural desire as mother, and they were sometimes ready to take the risk. The fertility desire of the participants

is also influenced by the age of the woman (women younger than 40 years have more fertility desire compared to older women) and, which is supported by the Phase I (Structural Survey) of this study as well as the previous study of Craft et al. (2007). In similar to other research many HIV infected women reported to be unwilling to discuss their fertility intention and desire with their health care provider for fear of the health care providers' perceived or actual judgemental attitude, disapproval and discrimination (Kaida et al., 2011; Withers et al., 2013). The qualitative findings of this study demonstrate the importance of incorporating discussion about the fertility intentions into HIV prevention and family-planning counselling. The Findings also suggest that counselling for healthcare provider works with PLWH are needed in the context to the northern communities as the providers play the crucial role in conveying accurate health information.

It is well documented in the literature that stigma and discrimination related with HIV and motherhood is common in many societies (Withers et al., 2013; Kaida et al., 2011). Though stigma was not the main focus of this study; similar findings were recorded. Consistent with earlier research, participants reported to feel hopeless about their life at initial stage of HIV diagnosis. At this stage, the women's HIV status influenced their decision not to have children in future; pregnancy was not the primary consideration (Richter, Sowell & Pluto, 2002). All the participants in this study were on financial assistance provided by the government. Consistent with other research findings, women reported concern about the negative impact of HIV on their own health, their financial state, and how this would affect the child. Linked with the issue of financial constraint was the experience of breast feeding and replacement feeding. The replacement feeding turned out to be concern of the women due to lack of money to buy baby food (Richter, et. al., 2002; Gombachika & Sundby, 2013). The financial constrain could be addressed by providing counselling and training for career

and creating more job opportunities for the PLWH by the government and different NGOs. Further research is recommended which may be helpful to address the issue better.

Limitation of the Study

This study covered more than 50% of HIV positive women receiving treatment in Prince George within the age range of 15-49 years. This study does not have any information of fertility desire of HIV positive men. It is understandable that men have significant influence on the decision of having children or not having children in both sero-discordant and sero-concordant couples. Another limitation is that, though the women who volunteered were similar to the known population in Prince George, the sample may have selection bias. The sample was not selected randomly but recruited from list of patients attending the clinics who have consented to participate in this study. It is expected that there are women who are HIV positive but not yet diagnosed or tested. These participants who volunteered may have been different from other HIV infected individuals in the surrounding communities, and they may have different knowledge and information about HIV infection and transmission than those who have not come to clinics. The end user can decide whether to accept these results as to generalize the findings in other rural communities of the Canada. For example, if the same research findings are applied to the people of Northern Ontario, there may be some constraints which include the different Aboriginal cultures, and different colonial influence of different European groups.

For Phase II of this research, it was my initial plan to conduct in depth interviews with all the consenting participants, but there were numerous challenges, including funding for the research, the long waiting period for permission from the Research Ethic Board of the University to conduct the study and from the study sites for data collection, time frame to complete the research, as well as accessibility and availability of the participants for interviews, limited the sample size. However, the findings of this study give us more

confidence to generalize the result for northern interior region (remote rural area) as our sample covered a little above than 50% of women who reported living with HIV in Prince George.

Implication of the Study

Implication for Future Practices

The results of this study revealed that a sizable number of HIV positive women intended to have children in future; this implies it is essential to support the HIV positive women make informed choices on their fertility issues. Health care providers who work with the women living with HIV need to provide non-judgmental counselling, create more awareness and remove misconceptions about the transmission of HIV by evaluating women's own feelings, goals and needs with respect to their reproductive decision making. Health care providers need to consider reflective counselling on contraception use and importance of using barrier methods as family planning and, as a primary preventive measure of STIs. Northern Health and other NGO's (for example Positive Living North, CINHS) may consider developing new policies and implementing them to improve the quality of life, reduce social and economic impact of HIV and to achieve the fertility goal of these marginalized vulnerable groups of women. Northern Health may consider developing a training program for the health care providers on Interpersonal Communication and Counselling (IPCC). The training will help to improve the health care providers' ability to elicit and understand the patients concerns, and deliver a patient-centred supports addressing individual's needs. Some recommendations for new policies may include establishing infertility services integrated with contraception services for HIV positive people, establishing day care centre for HIV positive children, easily accessible and available Prevention Mother-to-Child Transmission (PMTCT) services in Prince George.

Implication for Future Research

This study is a pioneer in addressing the fertility desires of women living with HIV in Northern interior of British Columbia. Two thirds of the sample were of Aboriginal descent. The sample of the study is heavily reflective of HIV infection among Aboriginal population with lower socioeconomic conditions and lower educational level. This fact over represented the poverty and HIV infection among the Aboriginal women in Prince George. Further research with a larger sample size of HIV positive women of other Northern regions, including their sexual partner and health care professionals would improve the generalization of the results. The examinations of the fertility issue from different settings (for example HIV-positive men's fertility desires and providers' perspectives towards PLWHA's childbearing intentions) are required for further understanding of the reproductive health issues among the HIV positive people. These would also help the health care providers and policy makers who are in a position for designing programmes and policies to address the reproductive issues of HIV-positive people in rural northern settings.

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Appendix A

Questionnaire for the study on socio-demographic characteristics and fertility desires of women living with HIV/AIDS.

Identification Number.....

1. Date of Birthdd/mm/yy

2. Ethnic group :

Aboriginal/First Nation/Métis/Inuit

White/Caucasian (European Ancestry)

Hispanic (Central and South America)

Black/African Canadian (e.g. West Indies, Africa)

South Asian (e.g. India, Pakistan, Sri Lanka)

Asian (e.g. China, Japan, Korea)

South East Asian (e.g. Philippines, Indonesia, Thailand)

Western Asian (e.g. Armenia, Iran)

Middle Eastern (e.g. Israel, Saudi Arabia, Iraq)

Other (please describe).....

3. Religion:

Christian:

Catholic

Jewish

Protestant

Buddhist

Others

Sikh

Muslim

Hindu

Other (please specify).....

4. What was the highest grade/level of school you COMPLETED?

No formal schooling

☐

Some elementary school

☐

Completed elementary school

☐

Some high school

☐

Completed high school

☐

Some trade school

☐

Completed trade school

☐

Some college/university

☐

Completed college/university

☐

Other (please describe)

5. Employment Status

Self Employed

☐

Employed Full time

☐

Employed Part time

☐

Retired on pension

☐

Social assistance

☐

Student unemployed

☐

Student employed Part time

☐

Others (Please specify)

6. What was your last year annual nearest income (before tax) and how many family members (including yourself) dependent on that income you reported?

(Circle the one A to M that apply)

A	<\$10,000 if 1 to 4 people (dependents)
B	<\$15,000 if ≥ 5 people (dependents)
C	\$10,000 to \$14,999 if 1 or 2 people (dependents)
D	\$10,000 to \$19,999 if 3 or 4 people (dependents)
E	\$15,000 to \$29,999 if ≥ 5 people (dependents)
F	\$15,000 to \$29,999 if 1 or 2 people (dependents)
G	\$20,000 to \$39,999 if 3 or 4 people (dependents)
H	\$30,000 to \$59,999 if ≥ 5 people (dependents)
I	\$30,000 to \$59,999 if 1 or 2 people (dependents)
J	\$40,000 to \$79,999 if 3 or 4 people (dependents)
K	\$60,000 to \$79,999 if ≥ 5 people (dependents)
L	\geq \$60,000 if 1 or 2 people (dependents)
M	\geq \$80,000 if ≥ 3 people (dependents)

7. Marital status:

Single	<input type="checkbox"/>	Separated	<input type="checkbox"/>
Married or equivalent	<input type="checkbox"/>	Divorced	<input type="checkbox"/>
Widowed	<input type="checkbox"/>		

8. What is the status of your partner?

HIV-positive	<input type="checkbox"/>
HIV-negative	<input type="checkbox"/>
Don't know	<input type="checkbox"/>
Not Applicable	<input type="checkbox"/>

9. Are you currently receiving Highly Active Antiretroviral Treatment (HAART)?

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
------------	--------------------------	-----------	--------------------------

10. Do you currently have menstrual cycle?

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
------------	--------------------------	-----------	--------------------------

11. Have you had sexual intercourse (vaginal) with male partners in the last SIX Months?

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
------------	--------------------------	-----------	--------------------------

12. Do you have Children?

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
------------	--------------------------	-----------	--------------------------

[a] If yes How many children do you have

[b] What are children's ages? (In years)

13. Do you intend to have children in the future?

Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Uncertain	<input type="checkbox"/>
------------	--------------------------	-----------	--------------------------	------------------	--------------------------

14. If yes to Q.13 how many more children do you still want?

14a. If you want to have more children, why do you want have children in the future?

.....

.....

.....

14b. If you do not want to have more children, what are the reason(s) for not wanting children in the future?

.....

.....

.....

14c. If you are uncertain whether to have more children or not, what are the factors of concern to you?

.....

.....

.....

15. How many pregnancies have you had since you tested positive?

.....

16. Were the pregnancies planned or intended?

Yes ☐ No ☐ Some were planned ☐

17. Does your Partner desire more children?

Yes ☐

No ☐

Don't know ☐

Not Applicable ☐

18. Were you/your partner used family planning / birth control before diagnosis with HIV?

Yes

☐

No

☐

19. If yes, which of the methods do you / your partner used? (Check all that apply)

Female Condom

☐

Male Condom

☐

"Pill" (oral contraceptive)

☐

Contraceptive Patch

☐

"Morning After" Pill

☐

Contraceptive Cream

☐

Intrauterine Device (IUD)

☐

Contraceptive Sponge

☐

Injection (Depo-Provera)

☐

Contraceptive Foam

☐

Diaphragm

☐

Cervical Cap

☐

Hysterectomy (uterus removed)

☐

Contraceptive Vaginal Suppository

☐

Female Sterilization ("tubes tied")

☐

None, I do not use birth control

☐

Male Sterilization (vasectomy)

☐

None, I am pregnant

☐

Rhythm

☐

None, I am trying to get pregnant

☐

Withdrawal

☐

None, I have just had a baby

☐

Implant (Norplant)

☐

Other (please describe)

20. Do you /your partner currently using any family planning / birth control?

Yes

☐

No

☐

[a] If yes what type of birth control you and/or your partner(s) using?(Please select ALL that apply)

Female Condom	<input type="checkbox"/>	Male Condom	<input type="checkbox"/>
"Pill" (oral contraceptive)	<input type="checkbox"/>	Contraceptive Patch	<input type="checkbox"/>
"Morning After" Pill	<input type="checkbox"/>	Contraceptive Cream	<input type="checkbox"/>
Intrauterine Device (IUD)	<input type="checkbox"/>	Contraceptive Sponge	<input type="checkbox"/>
Injection (Depo-Provera)	<input type="checkbox"/>	Contraceptive Foam	<input type="checkbox"/>
Diaphragm	<input type="checkbox"/>	Cervical Cap	<input type="checkbox"/>
Hysterectomy (uterus removed)	<input type="checkbox"/>	Contraceptive Vaginal Suppository	<input type="checkbox"/>
Female Sterilization ("tubes tied")	<input type="checkbox"/>	None, I do not use birth control	<input type="checkbox"/>
Male Sterilization (vasectomy)	<input type="checkbox"/>	None, I am pregnant	<input type="checkbox"/>
Rhythm	<input type="checkbox"/>	None, I am trying to get pregnant	<input type="checkbox"/>
Withdrawal	<input type="checkbox"/>	None, I have just had a baby	<input type="checkbox"/>
Implant (Norplant)	<input type="checkbox"/>		

Other (please describe)

.....

.....

21. Please circle the number that reflects YOUR feelings about the statement.

A. I expect to give birth to children in the future.



1

2

3

4

5



Strongly

Agree

Neither

Disagree

Strongly

Agree

Disagree

B. As I was diagnosed with HIV, I am more likely to have children than BEFORE I was diagnosed with HIV.



1

2

3

4

5



Strongly

Agree

Neither

Disagree

Strongly

Agree

Disagree

Thank you for completing the survey.

If in the future the researcher Farzana Amin wants to contact you for further information needed for the study would you be willing to be contacted?

Yes I would like to be contacted for

Clarification of survey response (only)

For further interview

No I don't want to be contacted in future

If "Yes" please complete the information on next page.

This page will be separated upon the completion of the survey and will be kept in a secured place

Identification Number:

Name of the Participant:

Address:

House/ Apartment #:

City:

Town:

Province:

Postal code:

Contact Number

Appendix B**Letter of Information (Phase I)**

Name of Research Project: Fertility Desires of Women Living with HIV/AIDS in Northern
British Columbia: A cross Sectional Survey.

Names of Researchers: Farzana Amin, Graduate Student, School of Health Science,
University of Northern British Columbia

Graduate Supervisor: Dr. Peter MacMillan, Associate Professor, Chair of the School of
Education, Cross appointed with the School of Health Sciences
University of Northern British Columbia

Date: _____

Dear Participant,

A) What is the purpose of the research?

The research is being conducted by Farzana Amin, a graduate student at University of Northern British Columbia under the supervision Dr. Peter MacMillan. This study will try to find out whether of women living with HIV/AIDS want to have babies or not and why want to have, or do not want to have, children in the future and the contraceptive behaviours in Northern Central BC (Prince George). My professional training and experience as a female medical doctor gives me, as a researcher a unique and well informed insight into the scope of this study: I hope that this research will benefit women living with HIV/ AIDS in the coming years by influencing social policy, community programming, and health services.

This research project will be the part of my Masters thesis for graduate degree (Master of Health Science in Community Health Sciences) with possibility for journal publication.

B) How respondent are to be chosen

In order to participate in this survey, women have to be diagnosed with HIV/ AIDS and be within 15 years to 49 years of age. Authorities of the locations selected for this study

were requested for the list of participants matched with the inclusion criteria of the study (women, aged 15-49, and living with HIV/AIDS).

Dr Abu Hamours' Clinic and/or CINHS will contact you as a potential identified research participant and request permission from you to contact, or to be contacted by, the researcher (Farzana Amin). I cannot have contact/have access any potential participants in any way until the authorities agree to provide me access at the study locations to obtain responses to my questionnaire.

C) What respondents will be asked to do?

I will give you a questionnaire with questions asking about socio-demographic status (for example your income per year, your relationship status, religion, age), contraceptive use, and whether or not you wanted to have children. In addition I am interested in your opinion on the reasons why you want to have, or do not want to have children in the future. If you agree to participate, I will give you the questions written on a paper, and then you, the person being interviewed, will provide response on the questionnaire. It will take 20 to 30 minutes to respond to all the questions. You will receive \$25 for your participation

D) Potential benefits and risks (if any) from the study

This research will not benefit you directly. I hope that the information learned from this study can be used in the future to benefit women living with HIV/AIDS. The information might help health care providers for planning to provide support for women with HIV/AIDS, in pregnancy planning, healthy lifestyle practices, contraception and others support if they want to have children. There is no perceived risk to you involved with this study as you only responding to some question without disclosing your identity. This study will have no foreseeable impact on your healthcare or treatment. You may experience un-comfortableness, uneasiness, or emotionally upset as a result of reading some of the questions in the

questionnaire. If this occurs, and you need any emotional support or counselling services you may contact following agency or persons:

Community Care Centre

1310 3rd Ave Prince George, BC, Canada. V2L 3E9

Telephone: (250) 960-6450

Sandra Barnes: HIV Nurse

303-2155 10 Ave Prince George, BC, Canada. V2M 5J6

Telephone: (250) 563-8284

Dr. Abu Hamour: Infectious Diseases Specialist

303-2155 10 Ave Prince George, BC, Canada. V2M 5J6.

Telephone: (250) 563-8284

E) The voluntary nature of your participation

You are free to decide whether to answer the questions or not. You can refuse to participate in the study or refuse to answer a specific question at any time without any impact. You will also decide whether or not you want to be contacted by the researcher in future for clarification of information you provided for this study. You will not provide any name or address if you do not want to be contacted by researcher. Your name will not appear in any of the results.

If you are between the age of 15-18 years, in order to participate in this study, the consent checklist need to be signed by your legal guardian.

F) Who will have access to respondents' responses? How anonymity and confidentiality is addressed? How information is stored, for how long, and how will it be destroyed?

Your information collected during research will be kept confidential and will only be accessible to me (Farzana Amin) and Dr. Peter MacMillan. The paper copies will be kept in a locked cabinet in the office of the supervisor Dr. Peter MacMillan (UNBC Room # 10 –

4026). The data file with confidential information will be stored in a pass-word protected computer and pass-word protected UNBC 'H' drive on the university computer intranet. Paper copies and the data file will be kept for 5 years after completion. Thereafter, paper copies will be shredded and the electronic copy (data file) will be permanently deleted. Only the summary report of the result will be shared with the organizations (Northern Health, CINHS and clinic of Dr. Abu Hamour) and the completed thesis will available at the UNBC library. The information collected from you will be used for thesis completion, conference presentation, report, and journal publication without disclosing any of your identity.

G) How to get a copy of the research results and to whom to contact in case questions arise.

The finding of this research will be shared by a presentation with Dr. Abu Hamour, Central Interior Native Health (CINH) authorities and with you in a lunch event at the end of the study.

If you have any question or wanted to have more information about this research and wanted to have final report, you may contact Farzana Amin, by electronic mail: amin@unbc.ca. You may also contact Dr. Peter MacMillan, University of Northern British Columbia, by electronic mail: Peter.MacMillan@unbc.ca. Information will be shared with you upon your request (either by face to face discussion or by mail). This must be in accordance to ethics requirements.

If you have any complaints about the project should be directed to the Office of Research (by electronic mail: reb@unbc.ca or by telephone: 250.960.6735).

Appendix C**Consent of the Participant (Phase I)**

Date: _____

Interviewer: Farzana Amin

Signature:

Having read the Letter of Information, I consent to the following items:

(Check only those that apply)

- I agree to participate in the research project
- I agreed to be contacted for a follow-up interview if necessary for clarification of information pertaining to this study, only.
- I agree to allow the information collected from me to be used for presentation, report, and journal publication without disclosing anything of my identity.
- If I am between the ages of 15-18, the consent checklist will be signed by my legal guardian.
- I understand that in case that I experience any emotional/psychological upset as a result of this study, I am being provided with a list of counselling/support services that I may access.
- I understand that I will be provided with \$25 for participating in this research project.

.....

Signature of the participant / legal Guardian

.....

Date

.....

Signature of the healthcare provider

.....

Date

Thank you

Appendix D

Letter of Information (Phase II)

Name of Research Project: Fertility Desires of Women Living with HIV/AIDS in Northern
British Columbia

Names of Researchers: Farzana Amin, Graduate Student, School of Health Science,
University of Northern British Columbia

Phone: 250 649 6290

Graduate Supervisor: Dr. Peter MacMillan, Associate Professor, Chair of the School of
Education, Cross appointed with the School of Health Sciences
University of Northern British Columbia

Phone: 250 960 5828

Date: _____

Dear Participant,

A) What is the purpose of the research?

The research is being conducted by Farzana Amin, a graduate student at University of Northern British Columbia under the supervision Dr. Peter MacMillan. This study will try to find out whether of women living with HIV/AIDS want to have babies or not and why want to have, or do not want to have, children in the future and the contraceptive behaviours in Northern Central BC (Prince George). My professional training and experience as a female medical doctor gives me, as a researcher a unique and well informed insight into the scope of this study: I hope that this research will benefit women living with HIV/ AIDS in the coming years by influencing social policy, community programming, and health services.

This research project will be the part of my Masters thesis for graduate degree (Master of Health Science in Community Health Sciences) with possibility for journal publication.

B) How respondent are to be chosen

Participants for the interview will be selected from the pool of women who have already participated in the phase one quantitative survey and consented to be contacted. Not all women who have consented and provided contact information will be contacted. Five participants will be interviewed. Participants that are residence in Prince George whose interview indicated that they may be more open to talk will be chosen for this interview. The participants may decline to be interviewed after it is explained to them that they are allowed to not participate at any time they so choose.

C) What respondents will be asked to do?

I (Farzana Amin) primary researcher will conduct the interviews. The interviews will be conducted using a semi-structured and open ended questionnaire. You have been asked as are others so that I can gain a broad understanding of yours views and views of other women who volunteered to response on prior survey. I will ask a series of short questions and will give you an opportunity to add detail(s) as you see fit. The questions will address several issues being HIV positive woman, having the intention to have children(s) or not children(s) as well as your views about supporting or not supporting pregnancy and the availability of facilities for women living with HIV in relation to pregnancy.

The interviews will be conducted in English at Dr. Abu Hamour's Clinic. Before the interview, a letter of information, with the details of confidentiality, limitations of the study and your rights as research participants will be read to you and then you will be requested to sign a consent from (in writing), thus you will give permission to be interviewed. The interview will be maximum 60 minutes long and you will receive \$25 for your participation.

D) Potential benefits and risks (if any) from the study

This research will not benefit you directly. I hope that the information learned from this study can be used in the future to benefit women living with HIV/AIDS. The information might

help health care providers for planning to provide support for women with HIV/AIDS, in pregnancy planning, healthy lifestyle practices, contraception and others support if they want to have children. This study has no foreseeable impact on your healthcare or treatment. However you may experience discomfort, uneasiness, or emotionally upset as a result of reading some of the questions in the questionnaire and you feel a need for emotional support or counselling services you may contact following agency or persons:

Community Care Centre

1310 3rd Ave Prince George, BC, Canada. V2L 3E9

Telephone: (250) 960-6450

Sandra Barnes: HIV Nurse

303-2155 10 Ave Prince George, BC, Canada. V2M 5J6

Telephone: (250) 563-8284

Dr. Abu Hamour: Infectious Diseases Specialist

303-2155 10 Ave Prince George, BC, Canada. V2M 5J6.

Telephone: (250) 563-8284

E) The voluntary nature of your participation

You are free to decide whether to answer the questions or not. You can refuse to participate in the study or refuse to answer a specific question at any time without any impact. You will also decide whether or not you want to be contacted by the researcher in future only if it is necessary to seek clarification on responses or gain greater understanding of the information you provided during this interview. A short questionnaire may provide an essential data that cannot be captured the depth of understanding come up from the interview. Your name or identity will not appear in any of the results.

If you are between the ages of 15-18 years, in order to participate in this study, the consent checklist needs to be signed by your legal guardian.

F) Who will have access to respondents' responses? How anonymity and confidentiality is addressed? How information is stored, for how long, and how will it be destroyed?

Your information collected during research will be kept confidential and will only be accessible to me (Farzana Amin) and Dr. Peter MacMillan.

Interviews will be manually or digitally recorded with the permission of the participants; only the researcher, paid transcriber (who will sign a confidentiality agreement form) and supervisor Dr. Peter MacMillan will have access to the information provided in the interviews;

The manual or digital recordings of the interviews will be kept in a locked filing cabinet in the office of the supervisor Dr. Peter MacMillan (UNBC office room), and the voice recordings will be transcribed into computer files. The computer files and transcripts will be stored in a pass-word protected computer and pass-word protected UNBC 'H' drive on the university computer intranet.

Any potentially identifying information will be removed or altered when input into the computer, a pseudonym will be used to identify participants in order to protect your identity.

Paper copies and the data file will be kept for 5 years after completion. Thereafter, paper copies will be shredded, audio and the electronic copy (data file) will be permanently deleted. Only the summary report of the result will be shared with the organizations (Northern Health, CINHS and clinic of Dr. Abu Hamour) and the completed thesis will available at the UNBC library. The information collected from you will be used for thesis completion, conference presentation, report, and journal publication without disclosing any of your identity.

G) How to get a copy of the research results and to whom to contact in case questions arise.

The finding of this research will be shared by a presentation with Dr. Abu Hamour, Central Interior Native Health (CINH) authorities and with you in a lunch event at the end of the study.

If you have any question or wanted to have more information about this research and wanted to have final report, you may contact Farzana Amin, by electronic mail: amin@unbc.ca. You may also contact Dr. Peter MacMillan, University of Northern British Columbia, by electronic mail: Peter.MacMillan@unbc.ca. Information will be shared with you upon your request (either by face to face discussion or by mail). This must be in accordance to ethics requirements.

If you have any complaints about the project should be directed to the Office of Research (by electronic mail: reb@unbc.ca or by telephone: 250.960.6735).

Appendix E**Consent of the Participant (Phase II)**

Date: _____

Interviewer: Farzana Amin

Signature:

Having read the Letter of Information, I consent to the following items:

(Check only those that apply)

- I agree to participate in the research project
- I understand that the researcher will conduct an in-depth interview with me and that this interview will last approximately 60mins (one hour).
- I understand and agree that the researcher will record information, and that the interviews will be manually or digitally recorded. All the digital recordings will be password protected and only be accessed by the researcher, the transcriber (who signed a confidentiality agreement form), and my supervisor Dr. Peter MacMillan.
- I understand that some of my actual words may be published in the written form, to capture the essence of my lived experience but any quotes will not be identified mine.
- I agree to allow the information collected from me to be used for presentation, report, and journal publication without disclosing anything of my identity.
- If I am between the ages of 15-18, the consent checklist will be signed by my legal guardian.
- I understand that in case that I experience any emotional/psychological upset as a result of this study, I am being provided with a list of counselling/support services that I may access.
- I understand that I will be provided with \$25 for participating when I have finished my interview.

- If in the future the researcher Farzana Amin wants to contact you only to seek clarification on responses or gain greater understanding.

Yes I would like to be contacted ☐

No I do not want to be contacted ☐

.....

Signature of the participant

.....

Date

.....

Signature of the legal Guardian (if applicable)

.....

Date

Thank you

Appendix F

Questionnaire for in-depth Interview (Phase II) Introduction

Thank you for participating in this interview. I greatly appreciate the effort and time taken to share your experience with me. This interview will be semi-structured, lasting maximum one hour. In the process of conducting the interview, I will be asking open ended questions that will be addressing the issue of HIV and intention to have children(s) or no children(s). If at any point you do not understand the questions or you are unclear, please feel free to ask for clarifications. **You are under no obligation to answer all questions: if you feel uncomfortable with a question, please let me know and we can skip to the next one.** All the information you will provide in the interview will be confidential. Your name and other personal information that could identify you will not be revealed in the final report of this study. You will receive \$25 for your participation

Semi-structured interview questions

- 1) Could you bring me back to the time when you first found out you are HIV Positive, (Probe where were you when you got the diagnosis, how did you feel, what was going on in your life at the time).
- 2) At what time did you first think about this condition of being HIV positive and its impact on you in relation to having / not having (more) children?
- 3) How important is it for you or other HIV positive women to have or not to have (more) children?
- 4) Can you tell me what it has been like for you having HIV and wanting to have children / or not wanting to have children. Probes: If the participant pauses, I may say "please tell me more about your experiences, or repeat her last sentence spoken.
- 5) What supports do you believe are necessary for HIV positive women who want to have children?
- 6) What are some of the reasons / barriers that might prevent HIV positive women from having children?
- 7) How are these reasons different or similar from other women's reasons (HIV negative women) to have / not have children?
- 8) Which of these reasons affected your decision to have children?
- 9) What are some of the changes that you suggest for you or other HIV positive women to make it more desirable to have children?
- 10) Is there anything you want to add?
- 11) Do you have any questions for me?

Thank you for your participation and sharing your life experiences with me.

Appendix G

Transcriber Confidentiality Agreement

Thesis Title: Fertility desires of women living with HIV/AIDS.

Research purpose: This research is to give voice to the subjective experience of stigmatized individuals living with HIV/AIDS in Prince George. Persons living with HIV/AIDS who agreed to participate in this study are asked to share their lived experiences of stigma, practices that they perceived to be stigmatizing and the impact of stigma on their response to HIV/AIDS diagnosis. Additionally, participants are asked to share how they are responding effectively to stigma and the factors that contributed to this and the impact this have on their life and living with HIV/AIDS.

I, _____, the research transcriber, agree to:

- Keep all the information shared confidential, by never sharing or discussing the contents of this research in any form or format with anyone, other than the Primary Researcher (Farzana Amin).
- Ensure the security of all research documents while in your possession.
- Upon completion of transcription, return all research information in any form or format.
- After completion of transcription and consultation with the primary research, erase and destroy all information regarding to the research that is not returnable to the researcher such as documents on the computer.
- I have read and agree to all the information.

Research Transcriber

Name	Signature	Date

Primary Researcher

<i>Name</i>	<i>Signature</i>	

Appendix H

Responses of Participants to desire or not desire to have children (Phase I)

Reasons to desire to have children:

1. To feel motherhood and pass my culture
2. To have someone to love
3. To feel mother hood and carry my culture
4. To love someone
5. To have a family , parenthood
6. To feel motherhood and have a family (didn't raise other children
7. Have a family and feel motherhood
8. Someone to care , to love
9. Have a family (didn't raise my other kids) and how to me mother
10. Have a family and experience as parent

Reasons to desire not to have children:

1. May have HIV positive child
2. I'm already in 40s
3. Risk to have HIV positive baby
4. Risk to have HIV positive baby
5. Old to have child (38 years) and not able to take care
6. Completed family and I'm old now
7. HIV can pass to baby
8. HIV can pass to baby

Participants who were not sure to have children (uncertain):

1. Worried child may have HIV positive baby
2. HIV may pass

Appendix I

Early Identified Themes: First two iterations (Phase II)

1. Feeling

Participant 1:

- I feel like I am not welcome to anywhere, nobody wants me
- I still cannot accept
- Never feel comfortable to ask such think (about pregnancy)
- I am so dirty
- They won't help me
- We are HIV positive we are not normal anymore (if you have HIV you are different)
- Too old too poor
- Burden to your doctors, to government

Participant 2:

- Empty
- Upset
- It was so painful
- I was in denial
- Don't want to face it
- I had to accept it
- I have to watch or be careful of my choices

Participant 3:

- I was sad.... afraid and angry
- It was tough for me
- I did an abortion. was horrified to have a HIV positive baby
- I really feel sad

- I was shocked with the news (I am HI V positive)

Participant 4:

- I was upset
- I just don't wanna accept except it
- Horrible day of my life
- not contagious (won't get HIV by touch)

2. Emotion

Participant 1

- Want to kill myself, tried to jump out of the building
- Crying like hell
- It was devastating , I Felt like I was drowning in a very cold sea”
- Don't want to have guilt to let him/ her HIV positive
- HIV racked my life

Participant 2:

- Everything become slow motion me , I just thought I am having a very bad dream
- It takes lots of afford to accept the fact...it is what it is I had to accept it
- HIV women need to be more open
- Have to think a lot

Participant 3:

- I can't sleep or eat for a month
- If a women is not HIV positive she don't have fear to be hated by others
- A normal women can easily get pregnant if she want ... not like us

Participant 4:

- Become dirty junky women with one word “ I'm HIV positive
- Not important to have child in this age

3. Hopefulness

Participant 1:

- I wanted to have a baby to have someone to love
- I think that (baby) could give them hope to live healthy.... inspire to live
- If someone told me I could have baby, I would surely have one
- You can have HIV free baby if you live healthy, take medication
- HIV positive women could be a good mother like others

Participant 2:

- Want to have a family ...I do want to have a child
- A normal life like other women
- I and my partner did lots of research through internet and we talked regularly.... asked my doctors about....yeah if I want I can have a baby
- They have a future, they are not alone
- Whole world out therelots of things going on
- Help us to be open and live healthy

Participant 3

- Always wanted to have a child
- I want to get pregnant ... I want to take another chance
- My partner wants it too

Participant 4:

- If anyone wants to have child, HIV shouldn't be a problem for having a baby. They should go for it is their choice
- We can also have child and family and have normal life like others

4. Hopelessness

Participant 1:

- No one told me I could have a healthy baby without HIV
- HIV took everything from me
- When HIV positive women wants a baby, they can't talk about it easily ...they have to be careful not to pass the infection to their baby. They have to deal with lots of stress and stigma
- Men don't want sick partner
- If you are HIV positive things are different
- Most of us don't have normal social life or family life
- It's too late (have children)

Participant 2:

- I thought my life was over
- I had no clue whether I could have a healthy child
- I thought I have no future at all
- Wanting children when I was not positive and now when I am positive it's a lots of differences

Participant 3:

- Knowing that I am HIV positive I didn't keep the baby. I did abortion
- Doctor told me it may not go to my baby but I didn't trust. Thought they just saying it because I am already four months pregnant
- I won't able to breast feed my baby
- Buying formula food is expensive.....need money

Participant 4:

- I started doing drug so that don't remember what's going on

- I am 46 year and not in good health
- I gamy child for adoption I couldn't raise them
- I was doing too much drug ... no time to raise child
- Difficult to raise your child like other women who are not HIV positive because they don't have face difficulties to find a job

5. Sense of belonging

Participant 1:

- I don't have money or support
- Women are born to be mothers, taking care of family
- It is important to have a baby especially if a women want to have oneif you are lonely like me... it is very important to have someone to love too
- I think I won't be lonely like now if I would had one child earlier

Participant 2:

- I am a young woman , it is natural that I would like to be a mother

Participant 3:

- It's not about HIV positive or HIV negative, It's about the women ...usually they want to have a child....it's kind of a natural thing

Participant 4:

- Didn't have any money or house
- Not important for me to have child in this age

6. Judgment

Participant1:

- I was young they should have thought that I would want a have a baby
- To take medicine

- They all the time telling me to take medicine.....use condom not to pass the infection, don't get other infections. They all talk about contraceptive ...tighten tubesno one ever asked "hey you want a family, do you want to have baby. There was no one to talk to.....no one ever asked me this question
- They won't help me I knew that, no need to ask
- There is shame you are HIV positive just deal with your own problems why want to bring another one
- No doctor or nurse will encourage you to have (baby)
- There is stigma
- Don't like to be poor and get hated by people.

Participant 2:

- Nurses were not so happy,
- Nurses were not excited
- I am sure nurses would be more supportive if a woman is not HIV positive and wanted their help or wanted to have child
- HIV positive women need to be open , have to ask otherwise no one would tell them about the thing they are looking for
- They (doctor /nurse) were not happy , I saw that I read in their face
- They (doctor /nurse) never willingly talk

Participants 4:

- If you are HIV positive you belongs to different group of people
- No one wants to be friends with you
- There is lots of stigma
- HIV can be transmitted by touching food
- My sister don't want me to touch or play with her kids

7. Education

Participant 3:

- Use protection to prevent getting other infections and pass HIV to others
- Need information and education for family and friends to have their support

Participant 4:

- Not everyone knows about HIV
- More information and more activity to reduce stigma about HIV
- Provide counselling

Participant 2:

- Lots of research through net

8. Services and supports

Participant 1:

- Need support for taking care of the baby like day care for an HIV positive baby
- Need to be able to talk with the doctor/nurse freely
- Need to be treated as other women who don't have HIV and want to have child
- More job opportunity for us

Participant 2:

- Develop HIV positive women groups (who are pregnant and who want to become pregnant, who already have children and young HIV positive women) to share our thought and experiences
- Doctor and nurse should ask the question whether they want a baby not
- Conversation with comforting voice and happy face (doctors/ nurses), assurance for help and help them to be more open and ask questions
- Have to go to Vancouver (not every hospital or every doctor will provide support)

Participant 4:

- **New support program**
- **Counselling services**
- **Have day care center for HIV positive babies**

Participant 3:

- **Need support money, emotional and physical support**
- **Need to go to Vancouver**
- **Easy to get information related to pregnancy for HIV positive women**
- **Need support from family and friends**

Appendix J

Letters of Approval

- Letter of Approval from UNBC REB for Phase I
- Letter of Approval from UNBC REB for Phase II
- Letter of Approval from CINHS
- Letter of Approval from Dr. Hamour for Phase I
- Letters of Approval from Dr. Hamour for Phase II
- Letters of Approval from Northern Health